

## DOCUMENT RESUME

ED 413 723

EC 305 997

AUTHOR Searl, Julia; Harris, Perri  
TITLE Community Integration Policy and Practice Abstracts, Third Edition.  
INSTITUTION Minnesota Univ., Minneapolis. Inst. on Community Integration.; Syracuse Univ., NY. Center on Human Policy.  
SPONS AGENCY National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.  
PUB DATE 1997-05-00  
NOTE 67p.  
CONTRACT H133B30072  
PUB TYPE Reference Materials - Bibliographies (131)  
EDRS PRICE MF01/PC03 Plus Postage.  
DESCRIPTORS Adults; Child Abuse; \*Community Programs; Criminal Law; Cultural Differences; \*Deinstitutionalization (of Disabled); \*Developmental Disabilities; Elementary Secondary Education; Employment; Family (Sociological Unit); Financial Support; Group Homes; Independent Living; Interpersonal Relationship; Leisure Time; Medical Services; Parents with Disabilities; Program Development; \*Public Policy; Quality Control; Self Determination; Sexuality; \*Social Integration; \*Transitional Programs; Trend Analysis  
IDENTIFIERS Facilitated Communication

## ABSTRACT

This document is a compilation of 166 abstracts of journal articles relevant to community integration for people with developmental disabilities. Articles were published from 1988 through 1997 and were selected for inclusion based on their relevance to policy and practice with research articles included if they had a strong applied emphasis. Abstracts are grouped under the following topics: abuse, communication--social relationships, community and supported living, criminal justice, education--inclusion, education--policies, employment, facilitated communication, families, funding, health care, institutional closure, leisure, multicultural issues, national trends, parents with disabilities, philosophy/ideology, policy, quality assurance, reproductive issues, self-determination, sexuality, social relationships, and transition to adulthood. (DB)

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# **COMMUNITY INTEGRATION POLICY AND PRACTICE ABSTRACTS THIRD EDITION**

**CENTER ON HUMAN POLICY  
SYRACUSE UNIVERSITY**

**MAY, 1997**

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**COMMUNITY INTEGRATION POLICY AND PRACTICE ABSTRACTS  
THIRD EDITION**

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UPDATED BY PERRI HARRIS**

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**MAY, 1997**

This is a compilation of abstracts of journal articles relevant to community integration for people with developmental disabilities. Articles were selected for inclusion based on their relevance to policy and practice. Research articles were included if they had a strong applied emphasis, with clear implications for contemporary policy and practice. This document is updated periodically to include current writing in the field.

Contributors to this document include Mair Hall, Mary Handley, Perri Harris, Kathy Hulgín, Julia Searl, Bonnie Shoultz, Steve Taylor and Pam Walker. We welcome suggestions of journal articles to add to our list of abstracts. Please send recommendations with a complete abstract, author, title and journal name and volume number.

Preparation of this document was supported through a subcontract to The Center on Human Policy, Syracuse University for the Research and Training Center on Community Living. The Research and Training Center on Community Living is supported through Cooperative Agreement No. H133B30072 between the National Institute on Disability and Rehabilitation Research (NIDRR), Division of Special Education and Rehabilitative Services, U.S. Department of Education, and the University of Minnesota, Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official opinion of NIDRR.

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## **ABUSE**

**Botash, A. S., Babuts, D., Mitchell, N., O'Hara, M., Lynch, L. & Manuel, J. (1994). Evaluations of children who have disclosed sexual abuse via facilitated communication. Archives of Pediatric Adolescent Medicine, 148 1282-1287.**

*Over the period of three years, 13 children who disclosed sexual abuse through facilitated communication were seen at a tertiary care hospital outpatient child sexual abuse program. Previously determined developmental diagnoses included mental retardation, speech delay, and autism. Physical examinations found that four of the children had evidence of sexual abuse, two had physical findings consistent with sexual abuse, one also disclosed the allegation verbally, and one perpetrator confessed. Although the results neither support nor refute validation of facilitated communication, they suggest that each child's case should be evaluated without bias.*

**Furey, E. M. (1994). Sexual abuse of adults with mental retardation: Who and where. Mental Retardation, 32(3), 173-180.**

*Over a 5-year period, of the 461 cases of sexual abuse of adults with mental retardation, 37% were confirmed by the Abuse Investigation Division of the Connecticut Office of Protection and Advocacy for Persons with Disabilities. As expected, most of the victims were women (72%); their average age at the time of the incident was 30 years. Victims, for the most part, had no problems communicating verbally and had few, if any, secondary disabilities. As is the case in the general population, the majority of the perpetrators were men (88%) and included other adults with mental retardation, paid staff, family members, and others. Most sexual abuse occurred in the victim's residence, and in 92% of the cases the victim knew his or her abuser. Results were discussed and several concerns raised.*

**MacFarlane, A. (1994). Subtle forms of abuse and their long term effects. Disability & Society, 9(1), 85-88.**

*Although there has been acknowledgement and some media attention to the sexual abuse of people with developmental disabilities, this paper focuses on the subtle abuse that occurs daily. Abuse occurs in residential facilities, schools, and sometimes in people's own homes, due in part to the inability of others to listen to an individual's choice. Despite policies that emphasize participation and choice, people with disabilities are often ignored and abused by those with power.*

**McCarthy, M., & Thompson, D. (1996). Sexual abuse by design: An examination of the issues in learning disability services. Disability & Society, 11(2), 205-217.**

*This paper is based upon ideas developed by the authors during their past 6 years work on issues of sexuality and sexual abuse in a wide variety of learning disability settings in Britain. The paper argues that some features of service design in themselves make sexual abuse more likely to occur. It suggests ways of reducing risk, which should work alongside the more usually suggested educative approaches to individuals and groups of vulnerable people.*

**Sundram, C. J., & Stavis, P. F. (1994). Sexuality and mental retardation: Unmet challenges. Mental Retardation, 32(4), 255-264.**

*The new challenges in supporting people with mental retardation in the community, the nature and extent of the problem of sexual abuse in programs serving this population, and the differing judicial approaches taken to assessing their ability to consent to sexual relations were discussed. Potential sources of provider liability for harm caused to program participants were explained, and recommendations to improve practices were offered.*

## **COMMUNICATION: SOCIAL RELATIONSHIPS**

**Ferguson, D. L. (1994). Is communication really the point? Some thoughts on interventions and membership. Mental Retardation, 32(1), 7-18.**

*This paper presents a brief account of communication interventions and describes recent developments in the field resulting in shifts in intervention focus, perspectives, and strategies. In examining communication interventions as one example of professional efforts to ameliorate the effects of disability, the author concluded that the real point of such efforts is not so much improved communication as membership in society. The concept of membership was explored, including the ways in which individuals construct stories that make the communication acts of individuals with severe disabilities commonplace and socially valuable. Efforts to foster communication (e.g., change behavior, adjust movement) should shift to ensuring that membership in society is achieved.*

**Kliwer, C. (1995). Young children's communication and literacy: A qualitative study of language in the inclusive school. Mental Retardation, 33(3), 143-152.**

*Interactive and literacy-based language use of young children within the context of an inclusive preschool classroom was explored. An interpretivist framework and qualitative research methods, including participant observation, were used to examine and analyze language in five preschool classes that were composed of children with and without disabilities. Children's language use included spoken, written, signed, and typed. Results showed complex communicative and literacy language use on the part of young children outside conventional adult perspectives. Also, children who used expressive methods other than speech were often left out of the contexts where spoken language was richest and most complex.*

## **COMMUNITY AND SUPPORTED LIVING**

**Bogdan, R. (1992). A "simple" farmer accused of murder: Community acceptance and the meaning of deviance. Disability, Handicap & Society, 7(4), 303-320.**

*For all their adult years the Ward brothers have been subsistence dairy farmers in a small rural community in central New York. In the spring of 1990 one of them was found dead and his brother, Delbert, was charged with murder and subsequently tried. A psychologist who testified for the defense put Delbert through a range of standard diagnostic procedures and declared he was "mentally retarded." Townfolks reacted to the events with a tremendous outpouring of unified support for Delbert and his brothers. Their reaction was so emphatic and so*

*pronounced it attracted regional and national media attention. Paralleling current interest in the integration of people with various disabilities into the community, this paper discussed this family's natural acceptance in the community and the nature of community support.*

**Clear, M., & Horsfall, D. (1997). Research and disability in a local community. Disability & Society, 12(1), 119-132.**

*This paper describes a study of the experience of disability in a local community. The study unfolded within a carefully constructed and collaborative framework, so that the people in whose interests the study was focused could inform its process, and take opportunities to benefit from it and each other. Outcomes included the establishment of a local support group, a family support project involving the University and the local community, and considerably developed understandings of neighborhood support and the experiences of disability, most specifically from the point of view of carers. Finally, a model of community support service was proposed. In conclusion, the paper highlights the processes of local collaboration and research. It describes research in which the actions taken and proposed to improve local supports were informed by the ongoing processes of research, and in turn the research process itself was informed by the local experiences of participants.*

**Colond, J. S., & Wieseler, N. A. (1995). Preventing restrictive placements through Community Support Services. American Journal on Mental Retardation, 100(2), 201-206.**

*A policy evaluation of Community Support Services, an assistance group created by the Minnesota Department of Human Services to prevent admission of individuals with developmental disabilities to large state facilities, was presented. The model of these out-reach services was described. Program evaluation data were presented. The possible effect of Community Support Services on admissions to large state facilities, characteristics of individuals served compared to those waiting for these services, cost-benefit issues of operating Community Support Services, and community service providers' satisfaction with these services were discussed. Issues related to the establishment and operation of Community Support Services were also presented.*

**Davidson, P. W., Cain, N. N., Sloane-Reeves, J. E., Giesow, V. E., Quijano, L. E., Van Heyningen, J., & Shoham, I. (1995). Crisis intervention for community-based individuals with developmental disabilities and behavioral and psychiatric disorder. Mental Retardation, 33(1), 21-30.**

*When individuals with a developmental disability experience a behavioral or psychiatric crisis, their community placement may be threatened. A model crisis intervention program for individuals with dual diagnoses was discussed and performance and outcomes of such a service for 267 children and adults reviewed. Analysis indicated that 69% of the individuals required only one crisis intervention. Of the 31% requiring two or more, nearly all were referred earlier than 2 years post initial crisis intervention. The central, gulf-bridging role of a crisis intervention service in a comprehensive, coordinated, community-based mental health system for dually diagnosed individuals was discussed.*



**O'Brien J. (1994). Down stairs that are never your own: Supporting people with developmental disabilities in their own homes. Mental Retardation, 32(1), 1-6.**

*Supported living for people with developmental disabilities challenges many common service policies, practices, and assumptions. Until recently, professionals assumed that such people who did not reside with their families needed to live in some kind of service facility. Today, a growing number of people with developmental disabilities have challenged this assumption by living, with personalized support, in their own homes. Meeting this challenge calls for new relationships among people receiving support, those who provide support, and families that are focused on assisting people with developmental disabilities to establish a sense of place, security of place, and effective personalized control over their homes and the assistance they require.*

**Sapey, B. (1995). Disabling homes: A study of the housing needs of disabled people in Cornwall. Disability & Society, 10(1).**

*This research was carried out between January and July 1993. The study was an evaluation of housing needs of disabled people who were wheelchair users through a process of consumer consultation. It was concerned to find out the extent and nature of that need whilst also testing out consultation through the use of research methods in comparison with a non-consultative approach taken by the local authorities. The nature of need was found to be qualitatively different from that found through the study of normative needs. A significant number of disabled people were being made more dependent by their housing and this was being reinforced by the agencies that were intended to help them. In particular, the failure to consult disabled people was leading the local authorities to make inappropriate plans for newly built housing while the major need for adaptations was being undermined by their operation of the Disabled Facilities Grant. The findings support the call from other writers that the solutions to housing problems will only come through viewing disability as a civil rights issue.*

**Wagner, B. R., Long, D. F., Reynolds, M. L., & Taylor, J. R. (1995). Voluntary transformation from an institutionally based to a community-based service system. Mental Retardation, 33(5), 317-321.**

*The transformation of a large, private, non-for-profit, church affiliated provider of residential services from an institutionally based to community-based service system was described. Closure of a 200-person ICF/MR facility was discussed. Factors influencing the decision to close the institution as well as the guidelines used in effecting the transformation were described. Finally, data were presented indicating that consumer and staff satisfaction and judgement of program quality remained high during the period of transformation.*

## **CRIMINAL JUSTICE**

**Calnen, T., & Blackman, L. S. (1992). Capital punishment and offenders with mental retardation: Response to the Penry brief. American Journal on Mental Retardation, 96(6), 557-564.**

*The Supreme Court recently decided that the death penalty as it applies to persons with mental retardation is not a violation of constitutional protection from cruel and unusual punishment as long as juries consider the convicted person's disabilities during trial proceedings. Advocates for persons with mental retardation have argued that because their disability reduces culpability*

*in capital offenses, the death penalty is always inappropriate. In this paper the authors argue that the latter position makes unwarranted categorical assumptions about mental retardation, fails to consider the individualized and situation-specific determinants of culpability for a capital offense, and undermines the very assumptions required to restore respect and value for citizens with mental retardation as participants in society.*

### **Commentaries on Calnen and Blackman**

**Calnen, T., & Blackman, L. S. (1992). Mental retardation and capital punishment: Final comments. American Journal of Mental Retardation, 96(6), 573-575.**

*The authors reflect on articles published in American Journal of Mental Retardation that address the protection of people with mental retardation from capital punishment. They state that the articles were not able to provide a viable argument of categorical assumptions based on intellectual rationale. However, they did raise important moral and practical objections that included the pessimistic views of the legal system and the dubious system of classification which may exclude people with a known margin of error. They conclude that people with mental retardation can be protected from capital punishment when it is not an option for anyone, and/or that we need to increase services and expertise in our justice system.*

**Celeste, R. F. (1992). Commentary on "Capital punishment and offenders with mental retardation." American Journal of Mental Retardation, 96(6), 565-566.**

*Celeste argues that just as persons with mental retardation are not entitled to every job, that individual is not entitled to every criminal penalty. They need protection from the law due to their vulnerability. It is not realistic to assume that every person with mental retardation will be able to secure a highly sophisticated case-by-case defense that they would need. People with mental retardation should always be exempt from the death penalty.*

**Edgerton, R. B. (1992). On responsibility. American Journal of Mental Retardation, 96(6), 566-567.**

*Although the author finds capital punishment morally reprehensible, it is stated that a categorical exemption is wrong. Whereas it is understood that people with mental retardation are more often victimized, and that this often occurs within the criminal justice system, each case should be taken separately as to the particular circumstances.*

**Field, M. A. (1992). Executing defendants with mental retardation. American Journal of Mental Retardation, 96(6), 567-570.**

*Although Field agrees with Calnen and Blackman's argument of the counterproductivity of categorically excusing people with mental retardation from the execution, it is stated that they should not be subject to the death penalty. This is due to the point that we cannot be certain enough of the justice of the verdict.*

**Perske, R. (1994). Johnny Lee Wilson did not kill anybody. Mental Retardation, 32(2), 157-159.**

*Johnny Lee Wilson is currently in jail for a murder that somebody else admitted to. Although there was no physical evidence linking him to the scene of the crime, law officials saw him as an irrational person who 'confessed' to the murder after an investigative interrogation. Perske states that the police took advantage of Wilson's disability in order to solve the case.*

**Perske, R. (1994). Thoughts on the police interrogation of individuals with mental retardation. Mental Retardation, 32(5), 377-380.**

*Perske gives examples of three people with mental retardation who confessed to murder following police interrogation. He lists twenty characteristics that people with mental retardation tend to display at times of such distress, in answer to the question of why these men confessed so easily. He concludes that police should be trained to be aware of these issues, and that teachers and advocates could help do this. In addition, people with mental retardation should be taught how to react to questions from the police.*

**Schalock, R. L. (1992). Capital punishment and the dilemmas faced by law and mental retardation professionals. American Journal of Mental Retardation, 96(6), 570-572.**

*Schalock argues that although he agrees with Calnen and Blackman intellectually and ideally, people with mental retardation need to be protected from the death penalty due to their history of vulnerability in the criminal justice system, the harsh treatment often received, and a tendency not to exercise their legal rights. Professionals in the field of mental retardation should be available to assist the justice system.*

## **EDUCATION: INCLUSION**

**Alper, S., Schloss, P. J., & Schloss, C. N. (1995). Families of children with disabilities in elementary and middle school: Advocacy models and strategies. Exceptional Children, 62(3), 261-270.**

*During the elementary and middle school years, the needs of the child with disabilities center on acquiring appropriate academic, social, community access, and self-management skills. Family members must work together with a wide array of educational and related services personnel on behalf of their child with a disability and, at the same time, care for the needs of all members of the family. This article describes models and methods of advocacy, including self-advocacy, social support advocacy, interpersonal advocacy, and legal advocacy. Particular emphasis is placed on advocacy strategies for individual family members of the child with disabilities during the elementary school years.*

**Ayres, B. J., Meyer, L. H., Erevelles, N., & Park-Lee, S. (1994). Easy for you to say: Teacher perspectives on implementing most promising practices. Journal of The Association for Persons with Severe Handicaps, 19(2), 84-93.**

*Difficulties in translating innovations that have been validated by researchers into practices that will be used by practitioners are widely acknowledged. Nevertheless, research on systems change is sparse and teachers are seldom asked for their perspectives on the implementation*

of innovations. Special education teachers (n=83) from five states in regions known for their efforts to develop quality educational programs for students with severe disabilities were surveyed for their knowledge and skills, the actual presence of quality indicators in their programs, and difficulties they experience in implementing various most promising practices. The results indicate that the self-reported ratings of the presence of the indicators is correlated with both teacher skill and degree of implementation difficulty. Analyses of teachers' comments to an open-ended question reveal common concerns regarding time constraints and administrative support as major obstacles to implementation. The results are discussed in the context of the nature of education as an applied science, the need for a research-to-practice literature on the implementation process for practitioners, and the need to acknowledge explicitly the support variables present in research on educational innovations that may be essential to implementation in practice.

**Baron, S., Phillips, R., & Stalker, K. (1996). Barriers to training for disabled social work students. Disability & Society, 11(3), 361-377.**

*Disabled people wishing to enter higher education are confronted with a number of barriers, yet relatively little research has been carried out to identify the level and nature of such obstacles. The short study reported here was designed to examine policy and practice within a number of social work training institutions in Scotland. Interviews were held with disabled students and ex-students, course tutors and practice teachers. Barriers to training are identified in five main areas: first, the disabling physical environment; secondly, problems of typification (whereby global assumptions of impairment are made about individuals); thirdly, failure of equal opportunities policies; fourthly, the practice of treating all students in the same way, resulting in discrimination against a few; and, finally, self-censorship on the part of students. It is argued that the reluctance of some students to 'declare' an impairment is a rational response to the disabling policies pursued, albeit inadvertently, by institutions. The implications of these findings for policy and practice are discussed.*

**Brown, L., Long, E., Udvari-Solner, A., Davis, L., VanDeventer, P., Ahlgren, C., Johnson, F., Gruenewald, L., & Jorgensen, J. (1989). The home school: Why students with severe intellectual disabilities must attend the schools of their brothers, sisters, friends, and neighbors. Journal of The Association for Persons with Severe Handicaps, 14(1), 1-7.**

*A home school is the one a student with severe intellectual disabilities would attend if he or she were not disabled. A clustered school is a regular school attended by an unnaturally large proportion of students with intellectual disabilities, but it is not the one any or most would attend if they were not labeled disabled. Students who have severe intellectual disabilities should attend home schools so that (a) all children can be prepared to function in a pluralistic society; (b) the most meaningful and individually appropriate instructional environments and activities can be used; (c) parents, guardians, brothers, and sisters can have reasonable access to schools and services; and (d) a wide range of social relationships with students and others who are not disabled can be developed, maintained, and enhanced over long periods of time. The individualized educational program (IEP) of each student should include individually determined kinds and amounts of instruction in chronological age-appropriate regular education classrooms; on school grounds, but not in regular education classrooms; and in a wide variety of integrated nonschool environments that will actually be used during nonschool hours and days. Individually determined kinds and amounts of direct therapy and other needed services also must be provided from a home school base. Once a student with intellectual disabilities attends a home school, the next major issue becomes whether the student should be based in a regular education or in a special education classroom.*

**Gessler Werts, M., Wolery, M., Snyder, E. D., & Caldwell, N. K. (1996). Teachers' perceptions of the supports critical to the success of inclusion programs. Journal of The Association for Persons with Severe Handicaps, 21(1), 9-21.**

*Two mail surveys, one with a follow-up, were conducted to determine if consensus existed among general and special education teachers on (a) the conditions and supports that are critical to including children with substantial disabilities in general education classrooms and (b) problems faced in implementing inclusive education. The data were collected in three stages. The first stage was a questionnaire sent to teachers in Pennsylvania who had experience including children with moderate to severe disabilities in general education classrooms. Through two open ended questions, they were asked to identify critical supports for inclusion and major problems they faced when including children with disabilities. For the second stage, the same respondents were asked to rate the importance of the categories of supports and to rate the significance of the problems they faced. The results indicated that training, support from a team of professionals, and having help in the classroom were mentioned by a large portion of the respondents. The third stage involved a national sample of elementary, general education teachers responding to the open ended questions. The respondents in the national sample (teachers who may or may not have been involved in a supported program of inclusion) identified the same three supports more often than other supports.*

**Hamre-Nietupski, S., Nietupski, J., & Maurer, S. (1990). A comprehensive state education agency plan to promote the integration of students with moderate/severe handicaps. Journal of The Association for Persons with Severe Handicaps, 15(2), 106-113.**

*Attempts to achieve integrated education for students with moderate/severe handicaps have grown considerably over the last 15 years. However, despite increased integrated educational opportunities for these students, wide variations in placement options continue to exist within and across the states. The authors propose that state education agencies (SEAs) must take a proactive, leadership role in promoting integration. A case study illustrating comprehensive systems-change integration strategies employed by the Iowa Department of Education over the past 6 years and the results for other states are discussed.*

**Hunt, P., Alwell, M., Farron-Davis, F., & Goetz, L. (1996). Creating socially supportive environments for fully included students who experience multiple disabilities. Journal of The Association for Persons with Severe Handicaps, 21(2), 53-71.**

*This investigation analyzed the effectiveness of an intervention designed to facilitate the social inclusion of three students who experienced significant physical and intellectual challenges and, for two students, dual sensory impairments. The children were full-time members of two first-grade and one fourth-grade classrooms. The individualized intervention package included three major components: (a) provision of ongoing information to classmates about the communication system, adaptive equipment, and educational activities of the students with disabilities in the context of naturally occurring interactions between the students and their classmates or during "club" meetings; (b) identification and utilization of various media that could serve as the basis for interactive exchanges between the focus students and others; and (c) ongoing facilitation by educational staff of social exchanges between students and their classmates through the establishment of a "buddy" system, arrangement of interactive activities across the day, and prompting and interpreting communicative exchanges when necessary. All*



aspects of intervention were implemented by educational staff including general education and inclusion support teachers, paraprofessionals, and related service personnel. An analysis of the interactive patterns between the focus students and others indicated that when the intervention was fully implemented, there were increases in (a) reciprocal interactions with peers, (b) focus student-initiated interactions, and (c) focus student-initiated interactions that were comments (with no increase in requests or protests). In addition, there were decreases in assistive interactions with paraprofessionals. The social validation of changes in interactive patterns between the focus students and their classmates was established through interviews with the student's friends and their teachers.

**Janney, R. E., & Meyer, L. H. (1990). A consultation model to support integrated educational services for students with severe disabilities and challenging behaviors. Journal of The Association for Persons with Severe Handicaps, 15(3), 186-199.**

*Students with severe disabilities who also exhibit serious behavior problems are a significant challenge to the provision of integrated educational services in neighborhood public schools. This report summarizes the components of a consultation model that utilizes locally available resources and expertise to support integrated school placements, along with specific efforts to remediate individual student needs. Follow-up placement information is presented for target students receiving project services during the 1986 to 1989 school years, including a description of both successful and unsuccessful outcomes. Procedures and results are discussed in the context of the need for consultation and additional support services for the school and home to help local education agencies achieve a zero reject model of services for students with challenging behaviors.*

**Janney, R. E., & Snell, M. E. (1996). How teachers use peer interactions to include students with moderate and severe disabilities in elementary general education classes. Journal of The Association for Persons with Severe Handicaps, 21(2), 72-80.**

*This study investigated the way teachers in five elementary classrooms used peer interactions to facilitate the inclusion of a student with moderate or severe disabilities. Four themes describing the strategies used to encourage and shape interactions between students with and without disabilities were identified: new rules about helping, "just another student," age appropriateness, and "backing off." The discussion focuses on the complexity of facilitating peer helping roles without encroaching on the social reciprocity found in friendships. The development of inclusion practices based on cooperation and mutual assistance for all students, rather than only for students with identified disabilities, is recommended.*

**Low, J. (1996). Negotiating identities, negotiating environments: An interpretation of the experiences of students with disabilities. Disability & Society, 11(2), 235-248.**

*This paper explores the experiences of nine students with disabilities pursuing degrees at a large Canadian university. An ethnographic approach was followed using face-to-face, unstructured interviews and a focus group to generate data. The analysis focuses on how these students negotiate disabled and non-disabled identities while negotiating the physical environment of the university campus. Low argues that these negotiatory processes are necessarily interconnected and inherently contradictory.*

**McDonnell, A. P., & Hardman, M. L. (1989). The desegregation of America's special schools: Strategies for change. Journal of The Association for Persons with Severe Handicaps, 14(1), 68-74.**

*There is strong philosophical, legal, and empirical support for integrated educational programs for students with severe disabilities. In spite of this support, significant numbers of students with severe handicaps continue to be educated in segregated special schools. This article briefly reviews the support for integration and presents a framework for planned educational change, based on the extant racial desegregation literature. This report includes a discussion of the logistical issues facing school administrators and an analysis of effective leadership roles in the change process.*

**Nabors, L. (1997). Playmate preferences of children who are typically developing for their classmates with special needs. Mental Retardation, 35(2), 107-113.**

*The social preferences of children who are typically developing towards peers with special needs in inclusive preschool classrooms were examined. Children with special needs received few positive playmate preference nominations, but not a significant number of negative nominations. Children were disliked if they were aggressive, irrespective of disability status. Interventions need to be focused on improving the social skills of children with special needs and teaching preschool age children who are typically developing to understand the behaviors of classmates with special needs.*

**Peck, C. A., Donaldson, J., & Pezzoli, M. (1990). Some benefits nonhandicapped adolescents perceive for themselves from their social relationships with peers who have severe handicaps. Journal of The Association for Persons with Severe Handicaps, 15(4), 241-249.**

*The perceptions of 21 nonhandicapped high school students were investigated in regard to the benefits they had experienced as a result of developing relationships with peers who had moderate or severe disabilities. Semi-structured interviews with the nonhandicapped students indicated their experiences resulted in six types of benefits: (a) improvements in self-concept, (b) growth in social cognition, (c) increased tolerance of other people, (d) reduced fear of human differences, (e) development of personal principles, and (f) interpersonal acceptance and friendship. Students also identified areas of difficulty they had experienced in their relationships with peers having disabilities. Results are discussed in terms of implications for policy analysis and research on social integration.*

**Schnorr, R. F. (1990). "Peter? He comes and goes...": First graders' perspectives on a part-time mainstream student. Journal of The Association for Persons with Severe Disabilities, 15(4), 231-240.**

*Part-time integration of students with moderate and severe disabilities into regular classes has become a common feature of special education programs. How regular education students think about their school experience, including part-time mainstreaming, can be a source of information for integration efforts, but these perceptions have received little attention in the special education literature. Participant observation and in-depth interviews were employed over a 7-month period to study a first grade class in which a student described as "moderately mentally retarded" participated on a part-time basis. This student spent most of his school day in a self-contained special education class. The findings reveal that these first graders had a*

common framework for defining their school experience. Their descriptions centered around themes of "where you belong," "what you do," and "with whom you play." Data collected about Peter, the part-time mainstream student, are interpreted according to this student framework. Findings indicate significant discrepancies between the student's definition of what it means to be part of first grade and the focus of the teacher's efforts to include Peter and present him as a member of the class.

**Sowers, J., & Powers, L. (1995). Enhancing the participation and independence of students with severe physical and multiple disabilities in performing community activities. Mental Retardation, 33(4), 209-220.**

*The effectiveness of a multi-element approach derived from factors to increase self-determination of middle- and high-school-age students with physical and multiple disabilities was examined. The approach includes equipment and performance adaptations, brief in-school simulation training, and instruction and support for parents and home assistance providers. The intervention was instituted with three students; a multiple baseline design was used. Student participation and independence dramatically increased after the intervention. Results suggest that this approach may be one solution to providing students with both inclusive education and community skill and activity instruction. The impact of the intervention on student self-determination was discussed.*

**Staub, D., Spaulding, M., Peck, C. A., Galluci, C., & Schwartz, I. S. (1996). Using nondisabled peers to support the inclusion of students with disabilities at the junior high school level. Journal of The Association for Severe Handicaps, 21(4), 194-205.**

*Qualitative research methods were used to conduct a study of an inclusion program at a junior high school in which typically developing students assisted and supported students with moderate and severe disabilities as they attended general education classrooms. There were two purposes for conducting this case study: first, to provide a description of how one school, with limited resources available, successfully included students with disabilities in general education classrooms; and second, to describe outcomes perceived to be associated with the student aide program for the students with disabilities and the student aides. Data were gathered over 2 years and included ethnographic field notes and interviews. The perceived outcomes that emerged from an analysis of these data are discussed in terms of their implications for future practice and research.*

**Vandercook, T., York, J., & Forest, M. (1989). The McGill action planning system (MAPS): A strategy for building the vision. Journal of The Association for Persons with Severe Handicaps, 14(3), 205-215.**

*The McGill Action Planning System (MAPS) is a planning process that places primary emphasis on the integral involvement of learners with disabilities in the school community (i.e., regular classes and other typical school environments and activities). The seven key questions that comprise the MAPS process provide a structure that assists teams of adults and children to creatively dream, scheme, plan, and produce results that will further the inclusion of individual children with labels into the activities, routines, and environments of their same-age peers in their school community. This article provides a detailed description of the MAPS process, including the structure used, content covered, and the underlying assumptions of the process. An example of MAPS planning for an elementary age child with severe disabilities is provided,*



*along with suggested modifications that have been used for secondary age students. The final discussion addresses practical considerations for using MAPS, including how it complements an ecological approach to curriculum development and areas requiring further development and evaluation.*

## **EDUCATION: POLICIES**

**Alper, S., Parker, K., Schloss, P., & Wisniewski, L. (1993). Extended school year programs: A community-driven curriculum model. Mental Retardation, 31(3), 163-170.**

*Appropriate education guaranteed to children with disabilities under P.L. 94-142 has been translated by the courts to mean more than 180 days of education. There is now a strong legal precedent establishing the right to an extended school year (summer school) for students with severe disabilities. The courts have left open to interpretation, however, issues related to the program implementation. Descriptions of extended school year programs vary widely and include respite for parents, continuations of the regular school year curriculum, and remediation in skill areas. The only consensus seems to be that these programs should be tailored to individual needs. In the present article a systematic approach to curriculum development for students with severe disabilities enrolled in extended school year programs was described. This approach is (a) community driven, (b) consistent with each student's IEP objectives for the regular school year, (c) tailored to the individual student, and (d) consistent with current best practices of teaching functional skills performed by individuals without disabilities in a variety of integrated nonschool settings. Student progress data were presented.*

**McDonnell, J., & Kiefer-O'Donnell, R. (1992). Educational reform and students with severe disabilities. Journal of Disability Policy Studies, 3(2).**

*Educational reform has had a significant impact on the structure of public education over the last decade. However, the needs of children with severe disabilities have essentially been ignored in this process. This paper explores the relationship between third-wave educational reforms and the development of public educational programs for students with severe disabilities. This examination highlights the striking similarities in focus and approach between these two initiatives. Issues which are preventing the inclusion of children with severe disabilities in reform efforts are identified and discussed.*

**Mudrick, N. L., & Gartin, B. C. (1996). The inclusion controversy: Emerging patterns in case law. Journal of Disability Policy Studies, 7(2), 43-55.**

*Neither P.L. 94-142 nor its amendments, the Individuals With Disabilities Education Act (IDEA) of 1990, refers to the terms "inclusion" or "mainstreaming," addressing only the issue of placement in the "least restrictive environment" (LRE) for students with disabilities. Beginning in 1989, the federal courts began to address the issue of the inclusion of students with disabilities into the regular education classroom as a method for meeting the least restrictive environment mandate of federal legislation. As a result, functional definitions of LRE and its impact on the issue of inclusion have emerged in case law decisions during the decade. These decisions have provided educators and administrators with guidelines concerning appropriate placements, use of records from other school districts for program and placement decisions, and types of required documentation. As litigation concerning inclusion increases, it is imperative that*

*educators be aware of and understand the implications of these legal decisions. The authors review federal and circuit court cases related to the issue of inclusion and interpret the impact these decisions are having on the special education process as well as the effect this controversy and subsequent legal decisions are having on the educators who are involved.*

**Preece, J. (1995). Disability and adult education - the consumer view. Disability & Society, 10(1).**

*Developments in recent years have shown an increasing interest in the educational needs and aspirations of disabled adults. There is still, however, limited research information representing the disabled person's voice. This paper describes the outcomes from a survey of the educational experiences of 44 physically disabled adults in the North West of England. The findings indicated that, usually, the earlier someone had acquired a disability, the less likely they were, as adults, to have achieved professional or higher qualifications, and that the level of qualifications reached among women being surveyed was particularly low. Barriers to course attendance reflect both attitudinal and practical access issues, with underachievement often the result of oppression from a variety of sources. Both positive and negative experiences from disabled adults form the basis of recommendations for an equal opportunities approach to adult education for disabled people around the themes of integration, self-worth, empowerment and consultation.*

## **EMPLOYMENT**

**Albin, J. M., Rhodes, L., & Mank, D. (1994). Realigning organizational culture, resources, and community roles: Changeover to community employment. Journal of The Association for Persons with Severe Handicaps, 19(2), 105-115.**

*Although adults with severe mental retardation were one of the primary target groups intended to benefit from supported employment when it first emerged, the vast majority continue to be served in segregated sheltered work or non-work settings. To change this picture, many have believed that resources currently invested in day activity and sheltered employment programs must be redirected to supported employment. Recent studies suggest, however, that most rehabilitation organizations are adding supported employment to their existing array of services, rather than pursuing total changeover from facility-based to community-based employment support. If these data reflect the national experience, the anticipated and necessary shift of resources from segregated to community employment services is not occurring. To supplement existing data, a telephone survey was conducted of eight rehabilitation organizations pursuing changeover. This paper provides information on the experience of these eight organizations related to their reinvestment and agency changeover to supported employment, and offers recommendations for the future.*

**Butterworth, J., Hagner, D., Kiernan, W. E., & Schalock, R. L. (1996). Natural supports in the workplace: Defining an agenda for research and practices. Journal of The Association for Persons with Severe Handicaps, 21(3), 103-113.**

*Although there is a growing consensus that including natural supports in the employment process is an important goal, there is considerable debate about the definition and appropriate role of these supports. This manuscript clarifies and extends current definitions of natural supports and proposes a working model to guide future research and practice. Primary*

*emphasis is placed on natural supports as a desired outcome of successful employment rather than a distinct model for support and as a contributing factor to higher level outcomes such as quality of life. From both a researcher's and a practitioner's perspective there is a need to shift emphasis from competing models of employment support to developing a better understanding of the relationship between specific job coach interventions and the desired outcome of effective natural supports.*

**Freedman, R. I., & Lynch Fesko, S. (1996). The meaning of work in the lives of people with significant disabilities: Consumer and family perspectives. Journal of Rehabilitation, 62(3), 49-55.**

*This article reports the findings of a qualitative research study utilizing focus groups which obtained the perspectives of people with significant disabilities and family members about their overall employment experiences, concerns, and expectations. Focus group participants responding to questions about job outcomes and satisfaction, work relationships, support at work, job obstacles, and job expectations. This paper summarizes the key themes which emerged in response to the focus group questions and highlights the similarities and differences among consumer and family perspectives on these issues. The implications of these findings for professionals working with individuals with disabilities and their families are summarized.*

**Hagner, D., Rogan, P., & Murphy, S. (1992). Facilitating natural supports in the workplace: Strategies for support consultants. Journal of Rehabilitation, 58(1), 29-34.**

*The purpose of this article is to examine some aspects of the traditional job coach model of supported employment that ignore or impede the formation of social relationships between supported employees and their co-workers and supervisors. Alternative strategies are offered, using a support consultant approach, in order to maximize the social inclusion of supported employees and the development of natural support systems. The strategies discussed include (a) using typical strategies to secure jobs, (b) building opportunities for interaction into the design of supported jobs, (c) adopting a consultant role with business, (d) working with established procedures for employee training, (e) learning the informal culture of workplaces, and (f) assisting in the identification of common interests among workers. Specific examples of each strategy are offered.*

**Holmes, G. E. (1993). The historical roots of the empowerment dilemma in vocational rehabilitation. Journal of Disability Policy Studies, 4(1), 1-20.**

*As a paradigm for human services, the concept of empowerment is coming of age. This article examines the history and philosophy of vocational rehabilitation (VR) in the public sector as a way of understanding VR's capacity to implement empowering services for people with disabilities.*

**Lunt, N., & Thornton, P. (1994). Disability and employment: Towards an understanding of discourse and policy. Disability & Society, 9(2), 223-238.**

*This article explores the nature of disability employment policy drawing on evidence from fifteen countries. In line with earlier sociological approaches to disability it describes two ways of framing policy in the area. These two paradigms are developed and used to critically evaluate employment policy under the headings: legislative measures, open employment-financial measures, employment support services and sheltered/supported provision. The dilemmas that*

may arise during implementation of policy are discussed and the consequence for the construction of an emancipatory employment policy. Finally, the article suggests some themes or dimensions that a coherent disability policy should have.

**Mank, D. (1994). The underachievement of supported employment. Journal of Disability Policy Studies, 5(2), 1-24.**

*A review of the status of the national supported employment initiative shows that thousands of individuals are benefiting from the initiative and that supported employment is offered by community programs in every state in the nation. Yet despite these successes, access to supported employment is severely limited, the quality of the outcomes is challenged, and the investment in change appears to be dwindling. If supported employment for persons with severe disabilities is to expand and improve to meet the growing demand, then communities and government alike must analyze both the successes and the problems of the supported employment initiative and create a new path to change. The purpose of this paper is to review the status of the supported employment initiative, explore the perception of its underachievement, and provide recommendations for recapturing the momentum of the initiative.*

**McCaughrin, W. B., Ellis, W. K., Rusch, F. R., & Heal, L. W. (1993). Cost-effectiveness of supported employment. Mental Retardation, 31(1), 41-48.**

*Monetary costs and benefits of supported employment to individuals, taxpayers, and society were assessed as was the cost-effectiveness of the nonmonetary benefit, namely, quality of life of employees, as a result of supported employment. Participants were 20 individuals from two Central Illinois agencies serving clients with developmental disabilities. Costs and effects were evaluated using benefit-cost-effectiveness analyses. Supported employment was found to be cost-beneficial from the perspectives of the supported employee, the taxpayer, and society over a 5-year period as programs move from sheltered employment. In addition, supported employment was also more cost-effective with regard to quality of life than was sheltered employment.*

**Mudrick, N. R., & Asch, A. (1996). Investigation and enforcement of a disability discrimination statute: Complaints of employment discrimination field in New York State. Journal of Disability Policy Studies, 7(2), 21-41.**

*This paper presents an analysis of 7,189 complaints of disability-based discrimination in employment filed with New York State and open between 1984-1994. The characteristics of the complainants, the employers, the complaints, and the resolutions are presented. The data show that the majority of disability discrimination complainants were not persons seeking jobs, but those who had jobs or were terminated from jobs. Approximately 40% of cases closed with a positive outcome for the complainant, with no discernible differences by type of disability. The New York State data are of interest not only because they indicate how a state civil rights law for disability operated before the American with Disabilities Act (ADA), but because they can suggest what the experience and the challenges may be in the enforcement of the ADA over time.*

**Peterson, M. (1995). Ongoing employment supports for persons with disabilities: An exploratory study. Journal of Rehabilitation.**

*Ongoing employment supports are critical for persons in supported employment. This study obtained detailed information regarding types of ongoing employment supports available in*



*programs and ongoing supports used with specific individuals. Results of the study indicated that ongoing support is an important issue that is not being adequately addressed. On the one hand, funding for extended job coach services and availability of case management services that focus on employment are limited. On the other hand, ongoing employment supports tend to focus on services provided primarily by human service personnel. Human service personnel in the study do not focus on linking employees with co-workers, employers, family, and community members who might provide assistance. The degree to which human service personnel provided supports to such natural supports was also limited. This study illustrates the present state-of-art and the need to redefine the roles and relationships of human service personnel, persons with disabilities, and naturally supportive relationships.*

**Pumplan, I., Fisher, D., Certo, N. J., & Smalley, K. A. (1997). Changing jobs: An essential part of career development. Mental Retardation, 35(1), 39-48.**

*Supported employment, by definition, assumes the need for ongoing support. Despite this, assumptions inherent within regulations and policies of federal and state rehabilitation systems appear to be at variance with this definition: Job placement is viewed as final and support is temporary. Consequently, retraining and replacement services following the termination of a job are an afterthought, job change is equated with failure, and retraining is a reaction to this failure. In contrast, models of career development for the general population assume that changing jobs is an integral part of career development. In this paper we have applied this more normative view of career development to the rehabilitation system and the provision of supported employment.*

**Rhodes, L., Mank, D., Sandow, D., Buckley, J., & Albin, J. (1990). Supported employment implementation: Shifting from program monitoring to quality improvement. Journal of Disability Policy Studies, 1(2), 1-18.**

*The national proliferation of supported employment services for people with severe disabilities has governmental funders and regulators scrambling for standards upon which to judge the adequacy of these new services. The task is complicated by the variability in both employer needs and service requirements for supported employees as well as the community resources available to meet these needs. Conventional monitoring provides some safeguards against major abuses to persons receiving services, but does little to satisfy consumer, advocate, or policymaker interest in promoting quality assurance in service provision.*

**Rogan, P., Hagner, D., & Murphy, S. (1993). Natural supports: Reconceptualizing job coach roles. Journal of The Association for Persons with Severe Handicaps, 18(4), 275-281.**

*This article presents four case examples that illustrate various strategies used by agency personnel to promote job supports for employees with disabilities while minimizing the intrusion of supported employment personnel. Specific strategies include: (a) using personal connections to enhance social support, (b) matching individual preferences and attributes to work-site social climates, (c) collaborating with work-site personnel to develop adaptations and modifications, (d) facilitating and supporting the involvement of work-site personnel, and (e) providing general consultations focused on person-environment factors that promote both the success of the supported employee and the overall business. Each of these strategies is discussed within a natural support framework in relation to reexamining job coach roles. The implications of the four case examples are discussed and areas for further research are suggested.*

**Rogan, P., & Murphy, S. (1991). Supported employment and vocational rehabilitation: Merger or misadventure? Journal of Rehabilitation, 57(2), 39-45.**

*Supported employment was conceptualized and developed according to several primary tenets and value-based assumptions. This article examines the current status of implementation in reference to these underlying premises: integrated work, long-term support, services to people with severe disabilities, and unconditional inclusion. Arguments supporting the need for sweeping changes in the federal-state vocational rehabilitation system to accommodate supported employment as it was originally intended are presented along with recommendations for such changes.*

**Trevino, B., & Szymanski, E. M. (1996). A qualitative study of the career development of Hispanics with disabilities. Journal of Rehabilitation, 62(3), 5-13.**

*Career development of Hispanics with disabilities was the focal problem of the current study. Participants were seven Hispanic women and three Hispanic men. Twenty interviews were conducted and recorded. Additional data were collected through in-depth questionnaires including both demographic information and open ended questions. A grounded theory qualitative methodology was used to identify, categorize, and connect themes. Triangulation, field notes, memos, member checks, and peer debriefing were used to address issues of reliability. Two overriding themes emerged. The first, career motivation, was defined by experiences relating to developmental work motivation, the meaning of work, and the hierarchy of work needs. The second, vocational behavior, related to personal attributes, disability and work, and barriers and supports.*

**Yang, H., Leung, P., Wang, J., & Shim, N. (1996). Asian Pacific Americans: The need for ethnicity specific disability and rehabilitation data. Journal of Disability Policy Studies, 7(1), 33-54.**

*The Rehabilitation Act Amendments of 1992 mandate that state and federal public vocational rehabilitation extend efforts to further include "traditionally underserved" populations. Section 21 of the Rehabilitation Act Amendments specifies the Asian Pacific American population as an "underserved" group, and other data indicate that they are the fastest growing minority population in the United States. Yet, current data related to rehabilitation and disability at the national level are unavailable for Asian Pacific Americans. This article uses data taken from the Hawaii vocational rehabilitation program to illustrate the need for Asian Pacific American data to be reported, not only in aggregate form, but also for each ethnic group within the aggregate. It proposes a policy change for the way data are gathered and collected for the Asian Pacific American population.*

## **FACILITATED COMMUNICATION**

**Cardinal, D. N., Hanson, D., & Wakeham, J. (1996). Investigation of authorship in facilitated communication. Mental Retardation, 34(4), 231-242.**

*The authors examined whether facilitated communication users, under controlled conditions, could transmit rudimentary information to a naive facilitator. Forty-three students across 10 classrooms were shown a single randomly selected word with their facilitator out of the room. The facilitator then entered the room and asked the student to type the word, which was recorded exactly as typed and later evaluated; approximately 3,800 attempts were conducted over a 6-week period. Results showed that (a) under controlled conditions, some facilitated*

*communication users can pass accurate information and (b) measurement of facilitated communication under test conditions may be significantly benefitted by extensive practice of the test protocol, which could partially account for the inability of several past studies to verify facilitated communication-user originated output.*

**Maurer, N. M. (1995). Facilitated communication: Can children with autism have a voice in court? Maryland Journal of Contemporary Legal Issues, 6(2), 233-282.**

*This article explores the phenomenon of facilitated communication (FC), and the implications of excluding FC as a means of participating in the legal system. It traces the introduction and widespread use of FC in the U.S. and examines the clinical (psychological education, and scientific) debate surrounding FC; considers how the clinical debate affects the legal debate concerning the admissibility of FC testimony in court; examines whether currently-used standards for admissibility of scientific evidence should apply to FC; examines the rights of people with disabilities to access to the courts through FC pursuant to the ADA and Section 504 of the Rehabilitation Act; compares FC to interpretation or translation as an accommodation in court; and recommends protocols for the use of FC in court proceedings to ensure that rights of victims as well as defendants are protected. It develops a definition of FC as a "form of testimony that can be screened for outside influence by empirical means," rather than as a form of scientific evidence in itself, and argues for assessing on a case by case basis the use of FC to provide such testimony. It recommends validation of the FC user's ability to communicate and clarification of the statements that apparently suggest abuse, and points out that by implementing suitable protocols which permit the use of valid FC in court, the legal system will give individuals with disabilities a voice in the system and an opportunity to be heard consistent with the ADA and society's goal of equal access to justice.*

**Salomon Weiss, M. J., Wagner, S. H., & Bauman, M. L. (1996). A validated case study of facilitated communication. Mental Retardation, 34(4), 220-230.**

*The case of a 13-year-old boy with autism, severe mental retardation, and a seizure disorder who was able to demonstrate valid facilitated communication was described. In three independent trials, short stories were presented to him, followed by validation test procedures with an uninformed facilitator providing physical support to the subject's arm. In Trials 1 and 3, several specific answers were provided that clearly indicated that the young man, not the uninformed facilitator, was the source of the information. Moreover, some responses seemed to imply that the subject was employing simple inferential and abstract reasoning. This case study adds to the small, but growing number of demonstrations that facilitated communication can sometimes be a valid method for at least some individuals with developmental disabilities.*

**Simon, E. W., Whitehair, P. M., & Toll, D. M. (1995). Keeping facilitated communication in perspective. Mental Retardation, 33(5), 338-339.**

*In this article, the authors present their perspectives on the implications of a study of facilitated communication they conducted. They argue that studies of the technique are too preliminary to conclude that it is not valid for all individuals and present a procedure to follow in continued validation on an individual level.*

**Mental Retardation's 1992 Vol. 32(4) Exchange of Views on Facilitated Communication**

**Taylor, S. J. (1994). Editor's introduction to the exchange of opinion on the risks and benefits of facilitated communication. Mental Retardation, 32(4), 299-300.**

*The editor of Mental Retardation comments on the decision to include a commentary on facilitated communication (FC) by Levine and Shane, followed by responses to their manuscript. The results provide thought-provoking positions that offer information for the readers. The article and the responses are included.*

**Levine, K., Shane, J. C., & Wharton, R. H. (1994). What if...: A plea to professionals to consider the risk-benefit ratio of facilitated communication. Mental Retardation, 32(4), 300-304.**

*The authors look at the risks of facilitated communication (FC), which include that if FC is found to be valid it would provide a means for people to express themselves effectively, and respect from others. They cite risks that are mostly based on the assumption that most communication originates with the facilitator, consciously or unconsciously. They include risks to individuals of the creation of a false persona, nonpreferred life changes, elimination of previously effective communication, and the delivery of inappropriate educational instruction. There are also risks to families and teachers, which include guilt around the previous interaction style, rejection of people who cannot facilitate, false abuse allegations, and guilt, confusion and anger of "debriefed" facilitators. They conclude that FC should only be used if and when validation studies have been done.*

**Ferguson, D. L., & Horner, R. H. (1992). Negotiating the facilitated communication maze. Mental Retardation, 32(4), 305-307.**

*Due to the confusion and unexplained reported events unknown to facilitators, the authors list three main issues that need to be addressed. They include (a) the issue of authorship, (b) the complexity of communication, and (c) the nature of evidence. There are certainly many cases where authorship cannot be attributed to the facilitator, and they advocate both more studies and for facilitators to question their role in contribution to the messages portrayed. FC reminds us how interactive and dynamic communication is, and how very complicated. The need to provide clear and unequivocal proof challenges our way of thinking about communication. Although the ambiguities will continue, we need to work toward obtaining more information on FC.*

**Goode, D. (1992). Defining facilitated communication in and out of existence: Role of science in the facilitated communication controversy. Mental Retardation, 32(4), 307-311.**

*Goode agrees with Levine et al.'s approach to a risk-benefit analysis, but not with their conclusion. The risks of not using FC includes the denial of a form of communication for a person who may be unable to communicate in any other way. Each individual needs to be assessed as to the decision of whether to use FC. FC cannot be scientifically proved or disproved by its very nature, and we need to make it available to people even as we sift through the ambiguities.*



**Halle, J. W. (1992). A dispassionate (if that's possible) observer's perspective. Mental Retardation, 32(4), 311-314.**

*The author clearly states that the purpose of this paper is to evaluate the arguments put forth by Levine et al. as an independent but not uninterested onlooker. A critique of their paper is given that includes the argument that FC is unfairly given more scrutiny than other modes of communication, and that due to the questionably ethical dilemmas of putting FC to a controlled study, most likely the possible benefits far outweigh the risks. Users of educational materials, or people who make those decisions for others, need to be educated in consumerism, based on the students' needs and the available information on product use. A common solution to this controversy is remote, due in part to the possibility that those on both sides of the evaluation process may have differing world views.*

**Hitzing, W. (1992). Reply to Levine et al.'s "Plea to professionals." Mental Retardation, 32(4), 314-317.**

*Hitzing states that both sides of the controversy of FC view the findings of the other as unbelievable. More rational discourse needs to take place, and it is concluded that Levine et al.'s risk-benefit analysis is seriously flawed and serves as an emotional appeal to halt a practice that they are opposed to. Risk-benefit analyses are done for medications, and no other communication program has been subjected to this interrogation. They also spend very little time on the benefits, although they do cite the possible benefits as far-reaching. Their emotionally laden language ensures the continuation of misunderstandings.*

**Levine, K., Shane, H. C., & Wharton, R. H. (1992). Response to commentaries on risks of facilitated communication. Mental Retardation, 32(4), 317-318.**

*The authors respond to the four commentaries written on Levine et al.'s first risk-benefit analysis. They showed how all of them concurred that more research needs to be done to demonstrate authorship. They continue to state that the potential serious concrete harm to individuals with developmental disabilities is of primary importance. Other types of communication do not carry these same risks, and therefore are not subject to such rigorous tests. Their goal is to prevent harm to individuals, families and the community.*

**Journal of The Association for Persons with Severe Handicaps' 1994 Vol. 19(3)**  
**Exchange of Views on Facilitated Communication**

**Biklen, D., & Duchan, J. F. (1994). "I am intelligent": The social construction of mental retardation. Journal of The Association for Persons with Severe Handicaps, 19(3), 173-184.**

*The focus of this article is to show that mental retardation is a concept constructed to account for selected events, behaviors, or phenomena. There are two views of mental retardation: the normative view and the competence view, and one's view defines one's research approach. Researchers who take the competence view carry out research in the tradition of ethnography or symbolic interaction, as opposed to the normative view which attempts to define the objective truths about various aspects of retardation. The conflict over FC can be seen in light of these two views of retardation, since one's definition of mental retardation, science and truth influences one's opinion on FC and authorship.*

**Green, G., & Shane, H. C. (1994). Science, reason, and facilitated communication. Journal of The Association for Persons with Severe Handicaps, 19(3), 151-172.**

*The most important issue in the debate of facilitated communication (FC) is to look at the evidence and methods used to answer the question of whether FC enables people with disabilities to demonstrate unexpected skills. The authors look at the research on the validity of FC and find it lacking. Even people who are purported to be typing on their own may be receiving subtle cues or prompts, and still lack objective evidence. FC is stated to be a practice unsubstantiated by scientific research and theory development. Large numbers of people with no training or credentials have been able to experiment on people with disabilities without safeguards. FC needs to be approved by human rights committees and the benefits demonstrated convincingly before it is used any more.*

**Halle, J. W., Chadsey-Rusch, J., & Reichle, J. (1994). Editorial introduction to the special topic on facilitated communication. Journal of The Association for Persons with Severe Handicaps, 19(3), 149-150.**

*The editors invited papers from the most visible proponents of each side of the controversy of facilitated communication. In addition, four responses were assigned on the basis of their expertise on communication, research methodology, and the fact that they had not previously taken a public stand. A list of questions was provided as use for consideration in discussion.*

### **Invited Commentary**

**Horner, R. H. (1994). Facilitated communication: Keeping it practical. Journal of The Association for Persons with Severe Handicaps, 19(3), 185-186.**

*Horner states that communication is the central process for choice making and individualization. Encouragement is given to not make the debate on FC primarily a research question, and to keep it focused on the practical issues that family members and teachers face. An emphasis is made to resolve the question of authorship. Until this is done, it is suggested that the facilitator's role should regularly be tested.*

**Kaiser, A. P. (1994). The controversy surrounding facilitated communication: Some alternative meanings. Journal of The Association for Persons with Severe Handicaps, 19(3), 187-190.**

*The focus of this paper is the meaning of the controversy over FC itself rather than the evidence supporting claims for and against the validity and replicability of FC. FC has arisen in a time of frustration from knowing too little about how to facilitate independence of persons with disabilities and being able to do less than we are able to know. Although we always seem to attempt to categorize, observe and improve the behavior of people with disabilities, we do not really know who they are. People with disabilities need to be seen from a more holistic perspective, and at the same time we need standards to evaluate new practices.*

**Whitehurst, G. J., & Crone, D. A. (1994). Social constructivism, positivism, and facilitated communication. Journal of the Association for Persons with Severe Handicaps, 19(3), 191-195.**

*Facilitated communication, a technique that is said to enhance the communicative abilities of individuals with severe language impairments, has engendered much controversy. Biklen and*

*Duchan (1994) and Green and Shane (1994) present two sides of this controversy. Biklen and Duchan argue that from a constructivist's perspective, the primary issue is the underlying cultural presuppositions regarding mental retardation and science rather than the efficacy of facilitated communication. Green and Shane present research evidence challenging the efficacy of facilitated communication within a positivist's framework. The authors present a brief review of science as viewed through positivists' and constructionists' lenses. Using the framework of social constructivism adopted by Biklen and Duchan, we disagree with them on three points: (a) even though the process of constructing scientific knowledge is strongly affected by human social, emotional, and cognitive processes, it also involves matters of fact that cannot be ignored; (b) social constructivists' accounts of science can be accepted as descriptive without being prescriptive; (c) although we cannot prove that belief systems, including positivism and social constructivism, are true or false in the larger sense, belief systems have differential consequences for technological changes of the type that are valued by persons with severe impairments of communication.*

**Williams, D. (1994). In the real world. Journal of The Association for Persons with Severe Handicaps, 19(3), 196-199.**

*The author, who has been diagnosed with autism, states that there has been inappropriate testing techniques based on faulty assumptions, and misinformation of how FC works or doesn't work that undermines credibility. Many people with autism are treated as "broken" versions of the tester, which may result in a brick wall between them. Autism's self-other problem relating to poor systems integration cannot be reduced to a "movement" problem, and we don't have answers for why or how FC works.*

## **FAMILIES**

**Agosta, J., & Melda, K. (1995). Supporting families who provide care at home for children with disabilities. Exceptional Children, 62(3), 271-282.**

*Over the past two decades, our response to children with developmental disabilities and their families has shifted dramatically, moving from an historical awareness of disability based in segregation and exclusion to one that favors the integration of people with disabilities into the mainstream of community life. Over this period, nearly all states have developed initiatives to provide families with a variety of supportive goods and services. This article explores the current status of family support in the United States, summarizing essential program features, program effects, and outstanding issues that must be addressed if the present momentum for family support is to be sustained.*

**Birenbaum, A., & Cohen, H. J. (1993). On the importance of helping families: Policy implications from a national study. Mental Retardation, 31(2), 67-74.**

*This study is a companion to a 4-year study (Birenbaum, Guyot, & Cohen, 1990) on financing health care for individuals with autism or severe mental retardation. The authors reported on nonmedical expenditures and opportunity costs pertaining to maintaining a child or young adult with serious developmental disabilities in the home or in residential care and discussed policy implications for assisting their families. The authors proposed that (a) personal care and family*

*support should be included in health care requirements, (b) family-centered care should be promoted, (c) appropriate programs and care should be provided for young adults no longer in school, (d) financing and organizing of family supports and subsidies should be administratively simple, (e) Medicaid should be expanded to increase use of home-and community-based services, and (f) financial support should be provided to families.*

**Cohen, S., Agosta, J., Cohen, J., & Warren, R. (1989). Supporting families of children with severe disabilities. Journal of The Association for Persons with Severe Handicaps, 14(2), 155-162.**

*This article addresses the issue of how best to provide families of children who have severe disabilities with the support services they need to maintain their well-being. Relevant federal and state programs for family-related services are analyzed, and current service themes are discussed. Principles for program design are presented and recommendations for policy are offered.*

**Giangreco, M. F., Cloninger, C. J., Mueller, P. H., Yuan, S., & Ashworth, S. (1991). Perspectives of parents whose children have dual sensory impairments. Journal of The Association for Persons with Severe Handicaps, 16(1), 14-24.**

*Although educators and other professionals acknowledge the importance of involving parents in their children's' education, few researchers have investigated parental perceptions of educational and related services. This qualitative study identified four major themes during interviews with 28 families whose children have dual sensory impairments. These concerns clustered around parental perceptions of a "good life" for their children, as well as their experiences with fear, frustration, and change. Implications from the analysis may assist teachers, related service professionals, and administrators working with families to understand more fully parental perspectives.*

**Hemp, R., Braddock, D., Lakin, K. C., & Smith, G. (1994). Trends and milestones: The growth of family support. Mental Retardation, 32(4), 319.**

*The authors show that although family support spending has increased dramatically over the past eight years, the percentage for MR/DD services is still very small. They look at the cash subsidies, respite care, and other family support for each state, with the total dollars spent on family support.*

**Llewellyn, G. (1995). Relationships and social support: Views of parents with mental retardation/intellectual disability. Mental Retardation, 33(6), 349-363.**

*From the professional perspective, parenting by people with mental retardation, or intellectual disability, is regarded with concern. Little attention has been paid to what constitutes social support for these parents. A qualitative design was used to explore views of parents with intellectual disability about their relationship and social support for their parenting. Most emphasis was placed on the support received from and given to their spouses or partners. Support was not always viewed as beneficial; rather, it was sometimes viewed as restraint as well as a resource for parenting. Parents also exhibited a preferred sequence in seeking help, beginning with their partners, then family members, and, finally, professionals. Implications in light of policy and service provision were discussed.*

**Mitchell, P. (1997).** The impact of self-advocacy on families. Disability & Society, 12(1), 43-56.

*The impact of self-advocacy on families of people with learning difficulties has rarely been instigated. A participatory research project is currently studying this question. This paper argues that adulthood is central. The meanings attached to self-advocacy by people with learning difficulties are examined to support this, and the family context explored to discover the likely experiences and influences which will condition the reception for self-advocacy. The early findings of the research—from discussions with self-advocacy groups—are presented. We should expect self-advocacy to impact on families and for this impact to exhibit itself in a variety of ways, but because of the experiences and conditioning of families, and of people with learning difficulties, the impact will be complicated. It is this real experience of self-advocacy and families which the research is investigating.*

**Mlawer, M. A. (1993).** Who should fight? Parents and the advocacy expectation. Journal of Disability Policy Studies, 4(1), 105-116.

*In the attempt to help parents become better educational advocates for their children with disabilities, an "advocacy expectation" has been created. This expectation runs counter to the philosophy of normalization. The advocacy expectation and its effects are critically discussed. To counter the expectation and its effects, changes in professional roles, funding priorities, and program development are recommended.*

**Morris, J. (1997).** Gone missing? Disabled children living away from their families. Disability & Society, 12(2), 241-258.

*Many disabled children spend most of their childhood in 'care', but not formally 'in care'. Research concerning disabled children has been dominated by a medical model of disability and by a failure to include the subjective reality of children themselves. There is also inadequate statistical information available concerning children who spend most of their time away from a family setting. The article looks at what we do know about such experiences, identifying some issues for future research.*

**Turnbull, A. P., & Ruef, M. (1997).** Family perspectives on inclusive lifestyle issues for people with problem behavior. Exceptional Children, 63(2), 211-227.

*Interviews were conducted with 17 families of children, youth, and adults with problem behavior (e.g., aggression toward others, property destructions, self-injurious behavior, and pica). From a larger study addressing many questions, the data reported in this article focus on inclusive lifestyle issues that are important to families. Results are organized into categories that emerged from the qualitative analysis, including family life, friendship issues, school issues, community inclusion, and supported living/supported employment. Themes suggest extremely scant and tenuous inclusive lifestyle supports for these people and their families. Key recommendations focus on expanded family support and priority topics for research and training.*



## **FUNDING**

**Brandon, D. (1994). Money for change? Care In Place, 1(3), 211.**

*People with disabilities are not empowered by changes in 'care in the community.' The Canadians have developed individualized funding and service brokerage which are influencing practice in the United Kingdom. There are three clear stages in the development of brokerage: ad hoc pressure largely by individuals; pilot schemes; and mainstream provision.*

**Fujiura, G. T., Foccoforte, J. A., & Braddock, D. (1994). Costs of family care for adults with mental retardation and related developmental disabilities. American Journal on Mental Retardation, 99(3), 250-261.**

*'Out of pocket' spending by families supporting an adult family member with mental retardation or related developmental disability was characterized and estimated. Annualized nonreimbursement spending among a sample of 99 Chicago-area households was evaluated through survey and telephone interview across 10 categories of routine daily living expenses and disabilities-related services. The average annual out-of-pocket cost was \$6,348. Average pre-tax income for the sample households was \$37,657. Although wealthier households reported higher levels of spending, the percentage of household income represented by out-of-pocket costs increased significantly as family incomes decreased. Results were discussed in the context of families as focus for service planning and public policy and the importance of the family to the nation's system of care.*

**Gettings, R., & Chapin, R. (1992). Improving state rate-setting and reimbursement policies for developmental disabilities services: A critical task for the 90's. Journal of Disability Policy Studies, 3(2), 1-19.**

*This paper discussed some of the broad considerations that must be weighed in designing and administering payment systems for community developmental disabilities services during the 1990s. Key features of the current policymaking environment are examined to convey a sense of the framework within which current state policies are being established. In addition, the authors (a) analyze the complex factors which state policymakers have to take into account in their efforts to improve present community rate-setting and reimbursement policies, and (b) outline major trends in state-level rate-setting practices over the past several years. The paper concludes with a discussion of the need for consensus on basic programmatic directions as a precursor to effective reimbursement design.*

**Herman, S. E. (1994). Cash subsidy program: Family satisfaction and need. Mental Retardation, 32(6), 416-421.**

*Families of children with severe developmental disabilities who were participating in a cash subsidy program were surveyed about their satisfaction with the program. They were also asked about their need for a variety of other services. Families were satisfied with the operation of the program and with the amount of the subsidy they received. Families indicated a need for more respite care or sitters more often than any other service. Respondents were found to use their subsidy for the types of services they said they needed.*

**Mayer, J. A., Heal, L. W., & Trach, J. S. (1992). Income allowance policies of state Medicaid agencies as work incentives or disincentives for ICF/MR residents. Mental Retardation, 30(4), 215-219.**

*Results of a survey of six Midwestern states demonstrated that although some state Medicaid agencies have had work incentive policies for ICF/MR residents for some time, others continue to utilize policies that are a disincentive to work. Policy changes toward employment incentives in state Medicaid agencies should improve work opportunities for workers with mental retardation at little expense to the government.*

## **HEALTH CARE**

**Anderson, L., Lakin, K. C., & Prouty, B. (1997). Trends and milestones: Medicaid long-term care recipients grew by 37%, costs by 25% in 3 years. Mental Retardation, 35(2), 147.**

*This chart documents the change in Medicaid long term care recipients.*

**Birenbaum, A. (1995). Managed care and the future of primary care for adults with mental retardation. Mental Retardation, 33, 5, 334-337.**

*This article describes changes in the delivery of medical care that may adversely affect adults with mental retardation with the shift to managed care. The author explains the potential of limited access to necessary services that may occur. He lists five likely outcomes of this shift in services and argues for the need to train medical professionals in the needs of people with developmental disabilities.*

**Braddock, D. (1996). Trends and milestones: Medicaid and persons with developmental disabilities. Mental Retardation, 34(5), 331.**

*This report shows by state the number of people with disabilities who receive Medicaid. The chart also estimates the number of persons with developmental disabilities who would lose long-term care services in the year 2002 under the 104th Congress Medicaid spending reduction proposals.*

**Braddock, D., & Hemp, R. (1996). Medicaid spending reductions and developmental disabilities. Journal of Disability Policy Studies, 7(1), 2-32.**

*The federal-state Medicaid program provides significant and important services for persons with developmental disabilities in the United States. The research presented here in an empirical analysis of current congressional proposals to reduce Medicaid spending and a study of the impact of those reductions for persons with developmental disabilities. Compared to current law, the implementation of congressional proposals to reduce Medicaid spending would decrease the number of Medicaid long-term care recipients with developmental disabilities by approximately 56,000 individuals in the year 2002. The implications of Medicaid block grants and related enrollment restrictions are analyzed in the context trends in the provision of services to persons with developmental disabilities in the United States.*



**Criscione, T., Walsh, K. K., & Kastner, T. A. (1995). An evaluation of care coordination in controlling inpatient hospital utilization of people with developmental disabilities. Mental Retardation, 33(6), 364-373.**

*All admissions of people with developmental disabilities to a community hospital over 3 years were examined to evaluate the impact of a coordinated care model on length of stay and hospital charges. Admissions were divided into two groups, those receiving either coordinated care (program group) or routine care by community physicians (usual care group). The program group had shorter average lengths of stay and lower hospital charges than did the usual care group, especially when charges were adjusted for case mix. Similarity of severity across the groups was measured by number of discharge diagnoses and Medicaid case weights. Over the 3 years, for the 115 admissions in the program group, these differences amounted to more than \$200,000 in potentially unnecessary hospital charges. Implications of care coordination services for community-based health care planning were presented.*

## **INSTITUTIONAL CLOSURE**

**Lakin, K. C., Prouty, B., Anderson, L., & Sandlin, J. (1997). Trends and milestones: Nearly 40% of state institutions have been closed. Mental Retardation, 35(1), 65.**

*These figures demonstrate that almost 40% of state institutions have been closed. The charts summarize closures since 1960 and project planned closures by the year 2000.*

**MacNamara, R. D. (1994). The Mansfield Training School is closed: The swamp has been finally drained. Mental Retardation, 32(3), 239-242.**

*The author, a former superintendent of the Mansfield Training School for 10 years, describes the plight of inmates. He describes the changes that the institution went through from a large facility that used residents as sources of labor, to the advent of small cottages (considered innovative) that still did not address people's needs. The author also reflects on his experience when he testified in a lawsuit that helped close the Mansfield Training School.*

## **LEISURE**

**Bernabe, E. A., & Block, M. E. (1994). Modifying rules of a regular girls softball league to facilitate the inclusion of a child with severe disabilities. Journal of The Association for Persons with Severe Handicaps, 19(1), 24-31.**

*Although many local recreation programs are opening their doors to individuals with disabilities, the vast majority of individuals with more severe disabilities still do not participate in community-based recreation programs. One reason for lack of participation, particularly in competitive team sports, is that many persons with severe disabilities lack the requisite physical and motor skills. The purpose of this study was to determine if it were possible to assist coaches and players in modifying select rules of a girls' fast-pitch softball league so as to*

*accommodate the skill limitations of a player with moderate to severe disabilities. Results indicated that the modifications were effective as suggested by her batting average and on-base average. Furthermore, modifications did not seem to affect her teammates or other teams as noted by no differences in time per inning when this student was included or total number of bases when she was playing defense. Anecdotal reports also found that the player was well received by her teammates and other teams, and that she improved her social and sports skills.*

**Browder, D. M., & Cooper, K. J. (1994). Inclusion of older adults with mental retardation in leisure opportunities. Mental Retardation, 32(2), 91-99.**

*Leisure satisfaction is associated with life satisfaction for older Americans. For those with mental retardation, obtaining inclusive leisure opportunities can be impeded by changes in health and social status, limited access to the community, underdeveloped leisure skills, and the need for support to participate in leisure opportunities. These challenges can be overcome through support for inclusion in the varied leisure opportunities generally available for older adults. Making such support possible may require conversion of traditional resources, such as adult day programs. We described the transition of one program towards providing support for inclusive leisure and made recommendations for future practice and research.*

**Dattilo, J., & Schelen, S. J. (1994). Understanding leisure services for individuals with mental retardation. Mental Retardation, 32(1), 53-59.**

*This paper was developed to promote understanding of the complex process of leisure service delivery for children and adults with mental retardation and encourage people to work together to enhance leisure opportunities in integrated settings. The meaning of several terms associated with leisure were clarified and limitations of past and existing leisure services presented. They discussed the belief that all individuals, including those with mental retardation, have the right to experience leisure. Suggestions were made for development of leisure services involving social integration with peers who do not have mental retardation, the facilitation of active participation, development of age-appropriate behaviors, provision of comprehensive leisure education services, encouragement of self-determined leisure participation, and systematic coordination and communication among practitioners and family members.*

## **MULTICULTURAL**

**Alston, R. J., Bell, T. J., & Feist-Price, S. (1996). Racial identity and African Americans with disabilities: Theoretical and practical considerations. Journal of Rehabilitation, 62(2), 11-15.**

*Knowledge about the psychological construct of racial identity is valuable for any rehabilitation professional who wishes to understand African American people, particularly African Americans with disabilities. The purpose of this article is to examine the implications of Cross' model of racial identity development for African Americans with disabilities. A brief historical perspective on racial identity theory and an exploration of the interplay between disability and racial identity will be offered. Lastly, implications for rehabilitation counseling practice and research will be provided.*

**Connors, J. L., & Donnellan, A. M. (1993). Citizenship and culture: The role of disabled people in Navajo society. Disability, Handicap & Society, 8(3), 265-280.**

*Cultural constructs of disabilities can vary from one culture to another and significantly affect how the individual with disabilities is perceived, accepted, and accorded citizenship rights and responsibilities. This anthropological study of Navajo individuals with disabilities investigates these cultural constructs in a non-Western society from the perspective of the Navajo community members. Factors analyzed include child-rearing practices, the Navajo concept of childhood, and Navajo notions of health and unwellness. Historical attitudes toward disabled people are also explored, as well as changing attitudes due to the influence of Western biomedical explanations and interventions.*

**Dennis, R. E., & Giangreco, M. F. (1996). Creating conversation: Reflections on cultural sensitivity in family interviewing. Exceptional Children, 63(1), 103-116.**

*This study examines culturally sensitive practices in family interviewing and developing individualized education programs. Participants were 14 professionals in the field of special education, who provided their perceptions and reflections on their experiences as members of cultural minority groups on the United States. The article reviews literature relevant to cultural sensitivity and family interviewing, describes the method and findings of the study, and discusses culturally sensitive practices in family interviewing, while avoiding stereotypes and generalizations. Recommendations for professionals include increasing their own knowledge base about other cultures; examining their own cultural biases; providing a family focus; allowing sufficient time for comfortable interviews; and considering times, place, and language needs.*

**Harry, B., Grenot-Scheyer, M., Smith-Lewis, M., Park, H. D., Xin, F., & Schwartz, I. (1995). Developing culturally inclusive services for individuals with severe disabilities. Journal of The Association for Persons with Severe Handicaps, 20(2), 99-109.**

*In this position paper, the authors argue that concerns about race and culture largely have been ignored with respect to students with severe disabilities. The authors caution, however, that variables such as acculturation, social class, and education must be included in any consideration of cultural identity to avoid stereotyping. Second, the authors use the term "cultural inclusion" to indicate the need to address cultural features directly when planning for inclusion of students with severe disabilities. In this paper, the authors propose essentials of a culturally inclusive approach to building relationships with families and to assessment, placement, instruction, and programming for such students. Third, the authors call for a multicultural emphasis in personnel preparation programs, with a focus on process rather than cultural content. The paper concludes with suggestions for a research agenda.*

**Harry, B., & Kalyanpur, M. (1994). Cultural underpinnings of special education: Implications for professional interactions with culturally diverse families. Disability and Society, 9(2), 145-165.**

*This article identifies certain cultural assumptions that underlie special education policy and practice in the United States, and argues that unawareness of cultural relativity contributes to considerable cross-cultural dissonance in working with families from diverse backgrounds. With regard to policy, the article argues that, despite an ideal of parental participation, the medical note on which the law is based frequently results in misunderstanding between professionals and parents who do not share the same value system. Three aspects of such misunderstandings are explored: The way disability is defined, the power accorded to professional expertise, and the commitment to the decontextualized language of objective science. With regard to practice, the article further identifies four areas of parent-professional dissonance: Beliefs about parenting styles, education goals, family and community concerns, and the pragmatics of communications. Explicit awareness of cultural relativity is recommended as an essential step towards reciprocal relationships with families from diverse backgrounds.*

**Rogers-Dunn, J., & Blacher, J. (1995). African American families, religion, and disability: A conceptual framework. Mental Retardation, 33(4), 226-238.**

*In recent years, there has been considerable discussion of the impact of factors such as religion and ethnicity on the adjustment of families who have a child with disabilities. The role of religion is particularly relevant for African American families because of its historic influence on basic social and cultural values of this ethnic group. In this paper the authors explored issues of religion, disability, and ethnicity, with emphasis on how these factors relate to adjustment for families, particularly African American families. Findings gathered from diverse literature sources are reflected in a proposed framework to guide future research and policy development.*

**Shapiro, J., & Simonsen, D. (1994). Educational/support group for Latino families of children with Down Syndrome. Mental Retardation, 32(6), 403-415.**

*Experiences and observations based on an ongoing parent education support group for Mexican-origin Latino parents of children with Down syndrome were described. Culturally mediated concepts were discussed in terms of their relevance to specific aspects of group functioning, including group structure, membership, and leadership. Problems of particular concern to this population that might adversely affect maintenance and growth of the group were also examined. Finally, the potential value of such support groups for this parent population were considered as were guidelines for enhancing the group experience.*

## **NATIONAL TRENDS**

**Anderson, L., Sandlin, J., Prouty, B., & Lakin, K. C. (1996). Trends and milestones: States converting community ICFs/MR to HSBS waiver. Mental Retardation, 34(6), 402.**

*This report shows the number of states converting from community ICFs/MR to HCBS waivers. HCBS waivers provide a less regulated alternative to obtaining Medicaid cost-share to finance community services.*

**Braddock, D., Hemp, R., Lakin, K. C., & Smith, G. (1994). Trends and milestones: Continuing expansion of financial resources for MR/DD services. Mental Retardation, 32(6), 446.**

*The authors state that financial resources for developmental disabilities services have increased dramatically over the past 12 years. Rates are shown for each state as to how much money is spent on community services, and the percentage of growth between 1988-1992. In addition, states are ranked according to the percentage of funds that are spent on community services.*

**Hayden, M. F., Lakin, K. C., Braddock, D., & Smith, G. (1995). Trends and milestones: Growth in self-advocacy organizations. Mental Retardation, 33(5), 342.**

*This report shows the recent growth in the number of self-advocacy groups in the United States. From 1985 to 1990, the number of identified groups increased from 55 to nearly 750. A table provides the number of groups in each state that existed in 1990, 1993, and 1995.*

**Kiernan, W. E., Butterworth, J., & McGaughey, M. (1995). Trends and milestones: Movement from segregated to integrated services in the United States. Mental Retardation, 33(1), 64.**

*This report includes data about the percentage of people serviced in integrated and segregated services in each state in the United States. It shows that the percentage of those serviced in integrated services has increased. There is great variance, however, between the states. In some states this increase is accompanied by decreases in the percentage of people serviced in segregated services. In many states, however, the trend is toward offering integrated options to people entering the service system, but not toward moving people out of segregated services.*

**Lakin, K. C., Braddock, D., & Smith, G. (Eds.). (1995). Trends and milestones: Milestones reached in ICF/MR utilization. Mental Retardation, 33(4), 271.**

*This report compares expenditures through the Medicaid Intermediate Care Facility for the Mentally Retarded (ICF/MR) program and the Medicaid Home and Community Based Services (HCBS) program. It provides information on the number and changes between 1989 and 1994 in ICF/MR and HCBS participants. For the first time in 1993 and 1994, ICF/MR spending decreased while HCBS funding continued to increase.*



**Lakin, K. C., Braddock, D., & Smith, G. (Eds.). (1995). Trends and milestones: Children and youth in state MR/DD institutions. Mental Retardation, 33(4), 203.**

*This report shows how children and youth have been the primary beneficiaries of the deinstitutionalization movement. Data show the proportions of children and youth in state institutions.*

**Lakin, K. C., Braddock, D., & Smith, G. (Eds.). (1996). Trends and milestones: Majority of MR/DD residential service recipients now in homes of 6 or fewer residents. Mental Retardation, 34(3), 198.**

*This report shows that a majority of those who receive MR/DD services are living in homes of 6 or fewer residences and that less than 100,000 people living in MR/DD residences are living with 16 or more people. The chart also shows that over 23% were living in homes with 3 or fewer people.*

**McGaughey, M. J., Kiernan, W. E., McNally, L., & Scott Gilmore, D. (1995). A peaceful coexistence? State MR/DD agency trends in integrated employment and facility-based services. Mental Retardation, 33(3), 170-180.**

*National survey data reported by the state MR/DD agencies for integrated and segregated employment and facility-based nonwork services provided during FYs 1977 and 1990 were examined. The percentage and total number of individuals in integrated employment grew significantly across the 2 years. However, there were no significant changes in the percentage or number serviced in facility-based settings. State MR/DD agencies continue to fund a dual services system, with the vast percentage of total resources allocated to segregated programs. Policy and funding incentives need to be developed to stimulate conversion of segregated services to integrated employment.*

**National Association of Developmental Disabilities Councils. (1990). Forging a new era: The 1990 reports on people with developmental disabilities. Journal of Disability Policy Studies, 1(4), 15-42.**

*This summary of an extensive report submitted to Congress and the Administration provides eight critical issues that affect people with developmental disabilities, such as housing and health care, and shows where the issues stand as of 1990, and what the Association hopes to see in the future. Key findings of people's lives are clearly outlined and serve as indicators of the need for additional policy in many areas that is clearly based on values that include full independence and productivity.*

**Smith, G., Prouty, R., & Lakin, K. C. (1996). Trends and milestones: The HCB waiver program: The fading of Medicaid's "Institutional Bias." Mental Retardation, 34(4), 262.**

*This chart reveals that Medicaid's "institutional bias" is fading and that more people are being served in the community.*



## **PARENTS WITH DISABILITIES**

**Young, S., Young, B., & Ford, D. (1997). Parents with a learning disability: Research issues and informed practice. Disability & Society, 12(1), 57-58.**

*This paper commences with an examination of the concept of parenting and then applies its findings to parents who have a learning disability. It is argued that views on parenting, drawn from mainstream developmental psychology from parents who do not have a learning disability can inform our thinking about parents who do have a learning disability and provide an agenda for future research. In particular, the authors look at skills-based approaches to parenting, parenting as a motivated activity, cultural and historical factors influencing parenting, and lay views on children and childhood. The conclusion was reached that, although an audit of what people with a learning disability believe and expect about children is valuable research, the critical issue is how this knowledge is applied in parenting practice.*

## **PHILOSOPHY/IDEOLOGY**

**Danforth, S. (1997). On what basis hope? Modern progress and postmodern possibilities. Mental Retardation, 35(2), 93-106.**

*Modern and postmodern versions of hope as they apply to services for persons labeled as having mental retardation were examined. Proponents of modernism construct hope as relying on an ever-improving science to accurately comprehend mental retardation and other disabilities and the effectiveness of professional interventions. This myth of scientific progress is traced in various forms through American intellectual history to the development of special education as interventionist social science. Advocates of postmodernism cast doubt upon the grand narrative of modernism and critique modern social science as perpetuating stigmatized "mentally retarded" identities through the exercise of power. A rhetorical analysis of the current controversy over facilitated communication demonstrates the utilization of the language of modern science for its power effects in special education discourse.*

**Elks, M. A. (1994). Valuing the person or valuing the role? Critique of social role valorization theory. Mental Retardation, 32(4), 265-271.**

*The view was presented that social role valorization is not an adequate reformulation and replacement for the principle of normalization due to (a) inconsistencies in application of a distinction between valuing the person and valuing the person's social role, (b) the fact that valued social roles do not automatically lead to culturally valued lives and identities, (c) social role valorization not being substantially less "trans-empirical" than normalization, and (d) the inadequacy of valued social roles in providing defense against the dynamics of social devaluation. The term **social role valorization**, in which the person and role are valued, is offered as a possibly more coherent replacement for the term **normalization**.*

**Wolfensberger, W. (1995). An "if this, then that" formulation of decisions related to social role valorization as a better way of interpreting it to people. Mental Retardation, 33(3), 163-169.**

*Social role valorization is interpreted as a high-order empirical social science theory that informs people about the relation between the social roles that people hold and what happens to them as a result and how to valorize (improve and defend) the social roles of people at risk of social devaluation. Because social role valorization is not a "religion," people must go to higher belief systems to determine whether and why other humans should be valued or devalued, whether the social valuation of others should be promoted, and which presumably effective means to this end are morally defensible or even imperative. Whether a pursuit of social valuation in certain cases has unacceptable implications can be in the domain of either "religion" or practical trade-offs.*

**Wolfensberger, W. (1995). Of "normalization," lifestyles, the Special Olympics, deinstitutionalization, mainstreaming, integration, and cabbages and kings. Mental Retardation, 33(2), 128-131.**

*In this article the author clarifies his formulation of the concept of normalization against claims that he has diverted the original focus on lifestyle to a focus on services. Wolfensberger compares his definition of integration with Nirje's original formulation which did not call for living in the mainstream of society, but merely in patterns that were comparable to those of the mainstream. He argues that normalization cannot be achieved within segregated activities and settings such as special olympics.*

**Wolfensberger, W., & Thomas, S. (1994). Obstacles in the professional human service culture to implementation of social role valorization and community integration of clients. Care in Place, 1(1), 53-56.**

*Social integration of people with developmental disabilities has been a very slow process. Social role valorization (SRV) is a principle of community integration that has many implications for social integration. However, professionalization impedes this process. Many examples are given of how many service providers themselves are not integrated and have no sense of how to integrate people with disabilities.*

## **POLICY**

**Altman, B. M., & Barnartt, S. N. (1993). Moral entrepreneurship and the promise of the ADA. Journal of Disability Policy Studies, 4(1), 21-40.**

*A sociological analysis of the passage of the Americans with Disabilities Act uses theories of deviance and social movements to examine the process which led to enactment of the law. Changes in the makeup of the "moral entrepreneurs" pushing for the Act and in the "framing" of the discourse surrounding the issues are two important elements contributing to the enactment. The role of "moral entrepreneurs" in the implementation and enforcement of the Act, since its passage, is also explored. Their continued active involvement in the process may be necessary if the full potential of the law is to be realized.*

**Conroy, J. W. (1996). The small ICF/MR program: Dimensions of quality and cost. Mental Retardation, 34(1), 13-26.**

*Dimensions of quality of life were compared for people living in small ICFs/MR versus other community living arrangements. Individual differences were controlled by using a matched comparison design. The data set contained 35 indicators of quality. Primary analyses were restricted to data from 1988 to 1992. Fifty-one people from small ICFs/MR were matched with people from community living arrangements. Subjects were matched on adaptive behavior, challenging behavior, age, and gender. Quality outcomes were superior for people in the non-ICF settings on 10 of the 35 measures. The ICFs/MR were not superior on any of the indicators. Results suggest that less intensively regulated and more flexible models of residential supports may produce superior outcomes at equal or lower costs.*

**Croser, M. D. (1995). Word from Washington. Mental Retardation, 33(1), 49-53.**

*In this report, the Executive Director of the American Association of Mental Retardation provides an overview of national disability-related activities that occurred in 1994, including a description of legislative activity and political appointments. She also describes the broader changes in political climate which pose a threat in the effort to maintain the rights and services for people with disabilities.*

**Hahn, H. (1993). The political implications of disability definitions and data. Journal of Disability Policy Studies, 4(2), 41-52.**

*The purpose of this analysis is to examine and to compare the conceptual, methodological, and operational implications of the medical and economic perspectives that have formed the bases of the traditional "functional-limitations" paradigm and the sociopolitical definition which is the foundation of the new "minority-group" model for research on disability. Both the medical and economic definitions have relied primarily on clinical methods. Whereas the medical approach has been operationally measured by limits on major life activities, the economic orientation has been measured by restrictions on the amount or kind of work that can be performed. By contrast, the sociopolitical definition, which focuses on the interaction between the individual and the environment, can be empirically assessed by measures of visibility and labeling. Self-identification is also an important index of the relative size and political strength of disabled persons. Because of the significance of new anti-discrimination laws, which appear to be based on the minority-group model, there is a pressing need to grant operational measures of the sociopolitical definition a position of parity in relation to the vast amount of data that have already been accumulated through the use of medical and economic concepts in government and other surveys.*

**Herr, S. S. (1995). Maximizing autonomy: Reforming personal support laws in Sweden and the United States. Journal of The Association for Persons with Severe Handicaps, 20(3), 213-223.**

*Reforming outmoded systems of guardianship requires that government assess personal support and related services. U.S. policy-makers and reformers in individual states have begun to question how current guardianship laws may disempower individuals with mental disabilities. This article explores some remarkable legal and public policy innovations in Sweden that*

*replace guardianship with personal support services such as mentors, administrators, "kontakt" persons, and personal assistants. It then examines the impact of Sweden's reforms on the autonomy, independence, and integration of its citizens and discusses possibilities for similar changes worldwide.*

**Johnson, T., Heimerl, S., Lanpher, J., Olsen, P., Rossiter, H., & Theis, D. (1995). Contributions and limitations of human services. Mental Retardation, 33(5), 332-333.**

*This paper was developed from a discussion by a group of parents, advocates, and service providers in Dane County, Wisconsin. Their purpose was to recommend a long-range direction for developmental disability services in their community. They provide a brief description of what they believe should be the goal of the service system followed by five "important limitations" of human services.*

**McFalls, W. J. M. (1995). Beyond treatment acceptability: A comment. Mental Retardation, 33(1), 57-58.**

*In this commentary the author addresses an article by Spreat and Walsh (1994) which supports the continued use of a hierarchical behavior treatment approach. McFalls argues that, though this has been a dominant approach in the field, it is not responsive to what people with challenging behavior need. He explains that it is in fact the restrictiveness of people's lives that is often the cause of behavior problems.*

**Michailakis, D. (1997). When opportunity is the thing to be equalised. Disability & Society, 12(1), 17-30.**

*This paper discusses the goal set out by the United Nations in its Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. The objective 'equalisation of opportunities' means both to render unlawful discrimination against persons with disabilities in every area of society, and to eliminate those every discriminatory conditions in society which render real participation impossible. The two conflicting approaches to handicap, the individual-centered and the person-environment approach, are both visible in the Standard Rules. This article suggests that the individual-centered approach is structurally related with the understanding of equal treatment as a relationship with formal characteristics, no matter what the setting in which it occurs, while the person-environment approach is related with an active social policy emerging from an understanding of equal treatment as a question of substantial right. There is thus a conflict inherent in the Standard Rules.*

**Middendorf, K. (1995). Presidential Address 1995 - The shifting paradigm: From rhetoric to reality. Mental Retardation, 33(6), 394.398.**

*As president of the American Association on Mental Retardation, Karen Middendorf reflects upon the state of the field. She begins by describing the shift in vision that is guiding the development of integrated services illustrated by several examples of people with disabilities whose lives have improved. This is followed by a list of lessons to guide service providers and ideas for bringing about change in the system.*

**O'Day, B. (1996). Re-authorization of the Rehabilitation Act: Comprehensive solutions or political satisficing? Disability & Society, 11(3), 411-427.**

*The Americans with Disabilities Act (ADA) is widely hailed as a sweeping piece of civil rights legislation that will dramatically affect the lives of individuals with disabilities in the US for generations. In contrast, the re-authorization of the Rehabilitation Act in 1992, and attempts to consolidate employment system for the general public in 1995 brought only modest reforms. How does comprehensive reform get on the US political agenda? What factors were present during passage of the ADA that were not present during reauthorization of the Rehabilitation Act? The author will use dominant political theories about policy making and agenda setting to answer these questions, and draw conclusions that will assist advocates in other countries in passing comprehensive civil rights legislation.*

**Pfeiffer, D. (1996). "We won't go back": The ADA on the grass roots level. Disability & Society, 11(2), 271-284.**

*The Americans with Disabilities Act (ADA) is a civil rights statute protecting people from discrimination based on disability in both the private and the public sectors. Using interviews with grass roots persons with disabilities across the USA--many of whom are experienced activists--and using other sources this article describes the reactions of the disability community in the United States to the passage of the ADA and its impact. Largely people with disabilities felt empowered by the ADA. However, a strong amount of cynicism is also found at the grass roots level regarding it. A revealing example of the empowerment felt by people with disabilities is the conflict in New York City over a proposal for non-accessible public toilets. Other reactions and developments are discussed including the possibility of the repeal or weakening of the ADA. A fundamental change occurred in the US with the passage of the ADA and the disability community will not allow that change to be undone.*

**Taylor, S. J. (1988). Caught in the continuum: A critical analysis of the principle of the least restrictive environment. Journal of The Association for Persons with Severe Handicaps, 13(1), 41-53.**

*This article presents a critical analysis of the principle of the least restrictive environment (LRE). The article begins with a review of the origins of LRE in professional writings and law and moves next to a discussion of how LRE has been operationalized in terms of a continuum concept. The author presents seven conceptual and philosophical flaws or pitfalls in the LRE principle itself, especially when it is applied to people with severe disabilities. The author then argues that an uncritical acceptance of LRE may lead to the establishment of a "new" community-based continuum and takes the position that many leading writings in the field can be interpreted to legitimate this new continuum. The conclusion of the article supports an unconditional commitment to integration and briefly contrasts integration with LRE as a guiding principle for the design of services and support for people with developmental disabilities and concludes with a note on the importance of viewing concepts in historical context.*



**Zola, I. K. (1993). Disability statistics, what we count and what it tells us: A personal and political analysis. Journal of Disability Policy Studies, 4(2), 9-39.**

*This paper begins with four reinterpretations about the prevalence, trends, temporality, and spread of disability. Together they lead to a different view of disability as quite pervasive in terms of sheer numbers, length of disability experience, and domains of life, as well as organ systems affected. The denial of this reality is related to our attempt to make disability "fixed" and "dichotomous," whereas it is better conceived of as "fluid" and "continuous." The costs of maintaining the former position are traced in notions of disability's "real" numbers and measurements, as well as in research, policy, and advocacy arenas. A redirection is suggested in terms of a more multidimensional approach and a purging of the inherent negative elements in current conceptions and measurements of disability.*

## **QUALITY ASSURANCE**

**Heinlein, K. B. (1994). Quality of care, quality of life: A rural perspective. Mental Retardation, 32(5), 374-376.**

*Quality of life, a subjective and transient judgement, is looked at in terms of how states establish parameters within which providers must work. The state of Wyoming is specifically looked at, which highlights the complications of care in a rural environment. A free market that drives price and quality is not recommended for rural areas, though consumer choice and least restrictive environment must be the driving force of the system.*

**Newton, J. S., Ard, W. R., Horner, R. H., & Toews, J. D. (1996). Focusing on values and lifestyle outcomes in an effort to improve the quality of residential services in Oregon. Mental Retardation, 34(1), 1-12.**

*Service systems for individuals with developmental disabilities are striving to assist people to obtain a higher quality of life, consistent with principles associated with continuous quality improvement. Through innovative, systematic, and widespread application of such principles, Oregon's Office of Developmental Disability Services is helping residential programs improve lifestyle outcomes for participants. Evaluations suggest that involved residential programs are maintaining implementation of the continuous quality improvement procedures and are finding them important and useful. More fine-grained research suggests that some programs are becoming more adept at identifying participants' preferred activities and incorporating them into Individualized Support Plans as well as improving participants' levels of physical and social integration.*

**Ray, N. K. (1995). From paper tigers to consumer-centered quality assurance tools: Reforming incident-reporting systems. Mental Retardation, 33(4), 239-247.**

*A practical framework for program administrators seeking to improve the effectiveness of their incident reporting and investigation procedures and practices was provided. Too often, these systems, which are designed by outside parties, are viewed by program administrators as instruments of risk exposure rather than viable tools for risk management and quality improvement. Program administrators were encouraged to take control of their incident-report*



systems by transforming them into viable consumer-centered quality assurance tools to meet the quality improvement needs of their own program. Specific performance indicators for effective systems were proposed, including consumer-centeredness; accountable reporting; thorough fact-finding; and prompt identification and implementation of corrective actions, fairness, and cost-effectiveness.

**Sundram, C. J. (1994). Quality assurance in an era of consumer empowerment and choice. Mental Retardation, 32(5), 371-373.**

*As opposed to the industrial definition of quality as a measurable quantity, the author states that there are many challenges to assuring quality for people with developmental disabilities. Quality is dependent on factors such as the ability to make choices. Agencies must emphasize community integration rather than just community placement.*

**Taylor, S. J. (1992). The paradox of regulations: A commentary. Mental Retardation, 30(3), 185-190.**

*This commentary serves as an introduction to a collection of articles on rules and regulations for people involved in the complex service systems serving people with developmental disabilities. He states that services are over-regulated, and that this contributes to an inability to utilize creativity in the provision of services, particularly services that rely on Medicaid funding. While a regulation may have originally been developed for a specific purpose, the translation of it into a setting often seems irrational and highly bureaucratic. Taylor states that regulations automatically dehumanize the people who receive services, and make even the smallest setting more similar than not to an institution. There is an inherent conflict, as a lack of regulation can result in substandard conditions within facilities. It is recommended that some basic standards be utilized, which specifically address safety and health issues, and that people with disabilities should be able to be supported in ways that they need as individuals, instead of living within bureaucratic facilities.*

## **REPRODUCTIVE ISSUES**

**Kallianes, V., & Rubenfeld, P. (1997). Disabled women and reproductive rights. Disability & Society, 12(2), 203-221.**

*Both the women's and disability rights movements have paid scant attention to the concerns of disabled women, especially involving sexuality, reproductive freedom, and mothering. Although their concerns may seem opposite of the women's movement's primary agenda, they are based on the same position: women must not be defined solely by biological characteristics and have the right to make decisions about their bodies and lives. Disabled feminists often support "reproductive rights," but also have different perspectives on abortion and reproductive technologies than non-disabled feminists.*

*The literature indicates that the reproductive rights of disabled women are constrained by: the assumption that disabled women are asexual; lack of reproductive health care, contraception, and sexuality information; and, social resistance to reproduction and mothering among disabled women. Disabled women are at risk for a range of undesirable outcomes, including coercive sterilization, abortion or loss of child custody.*

## **SELF-DETERMINATION**

**Brown, F., & Cohen, S. (1996). Self-determination and young children. Journal of The Association for Persons with Severe Handicaps, 21(1), 22-30.**

*The development of self-determination in individuals with severe disabilities is recognized as a critical goal for special education. Although increasing attention is being paid to this subject, efforts to date have focused largely on adolescents and young adults. It is highly unlikely that the characteristics associated with self-determination suddenly emerge in adolescence. This article calls attention to the need to look at the early roots of self-determination from a developmental point of view and examines the relationship of selected practices in early childhood special education to skills associated with self-determination. Curriculum and instructional approaches that appear to support the foundations of self-determination are discussed.*

**Brown, S. E. (1995). I was born (In a hospital bed)--when I was 31 years old. Disability & Society, 10(1), 103-108.**

*'I Was Born (In a Hospital Bed)--when I was 31 years old' is on one level an analysis of a personal experience and reaction to growing up with a disability. It is also a look at a process of integrating one person's awakening to the positive role a disability might play in someone's life with a common history of other individuals with disabilities and with the evolution of the disability rights movement in the US from the 1970s to the twenty-first century. The article is based on a speech delivered to a five-state disability rights conference in the early 1990s.*

**Cunconan-Lahr, R., & Brotherson, M. J. (1996). Advocacy in disability policy: Parents and consumers as advocates. Mental Retardation, 34(6), 352-358.**

*Advocacy for change, which stems from commitment and vision, should be a collaborative process among parents and consumers in partnership with professionals. Using surveys, interactive focus groups, and telephone interviews, we explored the concept and activities of advocacy experienced by parents and individuals with disabilities. Participants were identified through an advocacy and leadership training program, Partnership in Policymaking. Advocacy activities and supports and barriers to successful advocacy both for parents and consumers were identified. Suggestions for further research and action were proposed.*

**Hagner, D., & Marrone, J. (1995). Empowerment issues in services to individuals with disabilities. Journal of Disability Policy Studies, 6(2).**

*"Empowerment" has become a widely used term in discussions of disability and rehabilitation issues. However, the term has been given a confusing variety of meaning and interpretations. The meanings and some conflicting views of empowerment are reviewed. We argue that there is a great deal more clarity regarding how disability services currently limit empowerment than about what empowerment is, and we outline five core features of disability services which are said to be disempowering. Elements of a service system that overcome these limitations and promote empowerment are presented. Incorporating these elements will require a more radical restructuring of current service systems than many have supposed.*

**Kennedy, M. J. (1994). The disability blanket. Mental Retardation, 32(1), 74-76.**

*The author of this article describes the ways in which service providers look at and treat people with developmental disabilities. Services such as Medicaid require paperwork that breaks down every human activity into goals and objectives, without the input of the recipient. Services need to be provided in the context of individuals planning their own goals and expectations, which would demonstrate the respect and privacy that we all prefer.*

**Miller, A. B., & Keys, C. B. (1996). Awareness, action, and collaboration: How the self-advocacy movement is empowering for persons with developmental disabilities'. Mental Retardation, 34(5), 312-319.**

*In response to stigmatization and lack of opportunities in the United States, a self-advocacy movement by and for persons with developmental disabilities has grown. In parallel, in the empowerment literature in the social sciences, authors have sought to conceptualize the process of becoming empowered. There is little in the empowerment literature that fosters an understanding of the self-advocacy movement. In this paper, four relevant principles of empowerment (which concern gaining awareness of societal discrimination, individual rights, and personal strengths; taking action through participation in community organizations; and working collaboratively with supportive advisors) were considered. Through awareness, action, and collaborative support, self-advocates can transform themselves from marginalized targets of discrimination to respected citizens.*

**Reed, B. J., Fried, J. H., & Rhoades, B. J. (1995). Empowerment and assistive technology: The local resource team model. Journal of Rehabilitation, 30.**

*This article presents an overview of common service delivery models for the provision of assistive technology. A case is presented advocating a consumer driven model. The authors also describe such a model that has been practiced in Colorado. Additionally, some specific experiences, both positive and negative, from a local assistive technology project are shared.*

**Rhoades, D. R., McFarland, K. F., & Knights, P. G. (1995). Evolution of consumerism in rehabilitation counseling: A theoretical perspective. Journal of Rehabilitation, 61(2), 26-29.**

*The evolution of consumerism in rehabilitation counseling is shifting the focus from a hierarchical system to one that empowers those with disabilities. Factors which influence this evolution include: aging of populations, increasing visibility of women, advancing computer technology, environmental concerns, legislative initiatives, and the impact of cultural and racial diversity.*

**Wolfe, P. S., Oflesh, N. S., & Boone, R. B. (1996). Self-advocacy preparation of consumers with disabilities: A national perspective of ADA training efforts. Journal of The Association for Persons with Severe Handicaps, 21(2), 81-87.**

*To understand efforts of Mental Health/Mental Retardation/Developmental Disabilities (MHMR/DD) agencies to prepare clients with disabilities to assert their rights under the Americans with Disabilities Act (ADA), MHMR/DD personnel in 50 states responded to questions about self-advocacy needs of clients, nature of agency training in ADA self-advocacy, success of training strategies, barriers to client training, and perceived impact of the ADA. Respondents believe MHMR/DD clients need training in advocacy-related skills. They cite a number of barriers to client self-advocacy preparation. Respondents see minimal impact of the ADA on lives of agency clients; however, they are optimistic that future impact will be significant.*

## **SEXUALITY**

**Ames, T. H., & Samowitz, P. (1995). Inclusionary standard for determining sexual consent for individuals with developmental disabilities. Mental Retardation, 33(4), 264-268.**

*These authors argue that the right to develop personal relationships and express their sexuality has been denied people with developmental disabilities, mainly because of the difficulty in establishing their consent. They provide a standard of sexual consent they believe to be applicable to all people with developmental disabilities. Their standard begins with a philosophy to guide policies and includes indices for determining consent through verbal and non-verbal expressions.*

**Appleby, Y. (1994). Out in the margins. Disability & Society, 9(1), 19-32.**

*Using a social construction model of both disability and lesbianism, this paper focuses on the intersection of these two identities in questioning the accessibility of the lesbian community to women who are both lesbian and disabled. Whilst many physical barriers and lack of awareness can contribute to the exclusion of disabled lesbian women from the lesbian community, so also can the unquestioned assumptions by many able bodied lesbian women that disabled lesbian women are asexual and are somehow 'other,' and are 'different' from themselves. Disabled lesbian women may be forced to contend with, and resist, discrimination from both an able bodied heterosexist society and able bodied discrimination from within the lesbian community. Within the discussion of identities will be an attempt to problematize my own able bodied lesbian identity in both doing the research and in writing this paper. The challenges of addressing the complex issues of identity commonality, difference, and diversity will be discussed within a feminist perspective.*

## **SOCIAL RELATIONSHIPS**

**Lutfiyya, Z. M. (1991). "A feeling of being connected": Friendships between people with and without learning difficulties. Disability, Handicap & Society, 6(3).**

*Recently, programmatic attempts to encourage close ties between people with learning difficulties and typical citizens have increased. It is believed that such relationships will extend the assimilation of people with learning difficulties into society. The researcher presents the perspectives of four pairs of friends about the meaning of their friendships. The informants shared similar ideas and expectations about the characteristics of friendships in general. These included its mutual, exclusive, and voluntary nature; the right, obligations, and responsibilities of friends to each other; and the positive regard or affection found between friends. Despite efforts on the part of service providers to support the development of friendships between people with and without learning disabilities, the biggest barriers for the individuals in this study were the practices of the human service system, which curtailed opportunities for people which would have promoted the development and maintenance of friendships.*

**Newton, J. S., Horner, R. H., Ard, W. R., LeBaron, N., & Sappington, G. (1994). A conceptual model for improving the social life of individuals with mental retardation. Mental Retardation, 32(6), 393-402.**

*Fostering and improving the social relationships of individuals with disabilities have become recognized as legitimate roles for service providers. This is, in part, a logical outgrowth of a shift from services whose mission is seen as also including "lifestyle support." In this paper we reviewed ways in which social life has conceptualized and measured and suggested how such concepts might be integrated into a comprehensive model to spur research and development benefiting individuals with mental retardation.*

**Newton, S. J., Olson, D., & Horner, R. H. (1995). Factors contributing to the stability of social relationships between individuals with mental retardation and other community members. Mental Retardation, 33(6), 383-393.**

*Stability of social relationships may be an important indicator of lifestyle quality. Fourteen community members identified as being in long-term, socially stable relationships with one or more individuals with mental retardation provided answers to a quantitatively oriented questionnaire and participated in a more open-ended qualitative interview. In general, results indicated that the stability of the relationships were influenced by (a) the community members having previously served as staff members to the individuals with mental retardation, (b) their willingness to overcome logistical barriers that might otherwise have impeded their friendships, (c) their perception that the relationship included reciprocal social support, and (d) other idiosyncratic variables.*



**Taylor, S. J., & Bogdan, R. (1989). On accepting relationships between people with mental retardation and non-disabled people: Toward an understanding of acceptance. Disability, Handicap & Society, 4(1).**

*This article outlines the "sociology of acceptance" as a theoretical framework for understanding relationships between people with mental retardation and typical people. As a point of departure, the authors review sociocultural perspectives on deviance and explore their contribution to the study of mental retardation. Based on qualitative research on community programs for people with severe disabilities, the authors next examine the nature of accepting relationships and describe four sentiments expressed by typical people who form relationships with people with mental retardation: family; religious commitment; humanitarian sentiments; and feelings of friendship. The article concludes with a brief discussion of the sociology of acceptance for the field of mental retardation.*

## **TRANSITION TO ADULTHOOD**

**Cheston, R. (1994). The accounts of special education leavers. Disability & Society, 9(1), 59-69.**

*There has been comparatively little analysis of the ways in which pupils within special education describe themselves. This paper looks at the linguistic repertoires that leavers from special education in Central Scotland drew upon in order to account for their presence in what was seen by those around them as a stigmatizing environment. Eighteen special education leavers were interviewed: first of all either before or around the time that they left school; and then, for a second time, between twelve and eighteen months later. This study suggests that these special education leavers drew upon at least four different linguistic repertoires to explain their presence within a segregated environment. Two points emerge from these accounts: first that these repertoires accounted for the leavers' presence within special education without drawing upon notions of individual pathology; and secondly, that the accounts of these leavers changed according to the differing accounting tasks that the leavers were faced with. The implications of this research for those who work with teenagers and others who are forced to account for their presence in a stigmatizing environment is discussed.*

**Ferguson, P. M., Ferguson, D. L., & Jones, D. (1988). Generations of hope: Parental perspectives on the transitions of their children with severe retardation from school to adult life. Journal of The Association for Persons with Severe Handicaps, 13(3), 177-187.**

*Transitions within families are socially constructed processes that need to be understood in both their historical and their cultural context. This study explored how parents interpret the events and relationships surrounding the transition of their children with severe disabilities from school to adult life. The study used qualitative techniques to collect and analyze data from two sets of parents grouped according to their children's ages. Results indicated that the parents interviewed tended to perceive three distinct types of transition: bureaucratic, family life, and adult status. Generational patterns of parental response to these transitions are discussed in terms of professional relationships and self-reliance. A matrix of these response patterns is presented. The findings suggested several ways in which parent-professional cooperation around transition events might be improved.*



**Gallivan-Fenlon, A. (1994). "Their senior year": Family and service provider perspectives on the transition from school to adult life for young adults with disabilities. Journal of The Association for Persons with Severe Handicaps, 19(1), 11-23.**

*Transition from school to adult life has recently become a significant concern for policy makers, educators, adult service providers, and families who have a son or daughter with a severe disability. How individuals understand this transition can be an important source of information for efforts in this area; yet little or no specific data currently exist on how transition services are being provided and whether or not they facilitate successful outcomes for young adults with disabilities. The purpose of this research was to discover how transition from school to adult life is experienced and understood by particular young adults with disabilities, families, and service providers. Qualitative methods were utilized over a 16-month period to gather and analyze data on the transition process for 11 young people with disabilities. Eight main themes emerged from the data: differing future expectations for young adults with disabilities; inconsistent implementation of special education curricula and lack of inclusive educational practices; lack of transition related knowledge; hastily and poorly coordinated transition planning; a prevalence of restrictive views on employment and community living opportunities for adults with disabilities; low levels of family participation; outcomes of unemployment and isolation for most young adult participants; and significant benefits of supported employment and community inclusion. The study has implications for policy making regarding transition, and recommended service practices are offered.*

**Morningstar, M. E., Turnbull, A. P. & Turnbull, H. R. (1995). What do students with disabilities tell us about the importance of family involvement in the transition from school to adult life? Exceptional Children, 62(3), 249-260.**

*This qualitative study used focus groups to explore student perspectives on family involvement in the transition from school to adult life. Four focus groups, including students with learning disabilities, emotional and behavioral disorders, and mild mental retardation, identified pertinent issues concerning how families influence the development of a personal vision for the future, how students with disabilities perceive family involvement in transition planning, and how families influence the development of student self-determination. Results showed the importance to students of family input and support. Implications for transition planning, family roles for support during adulthood, and family-student-school partnership models are discussed.*

**Szymanski, E. M. (1994). Transition: Life-span and life-space considerations for empowerment. Exceptional Children, 60(5), 402-410.**

*Transition is a process that should empower students, families, and communities. This article integrates literature from counseling, rehabilitation, multicultural education, and special education to explain the importance of life-span considerations, including a focus on preschool and early school years, and the importance of the life-space factors of family, culture, and community. Principles of intervention for empowerment promote transition interventions that are maximally under the control of the student, promote independence and autonomy, are least intrusive, and are most natural for the chosen environment.*

**Thomson, G. O. B., Ward, K. M., & Wishart, J. G. (1995). The transition to adulthood for children with Down Syndrome. Disability & Society, 10(3).**

*This paper reports on the transition pathways to adult status of 35 young adults with Down Syndrome over a six-year period (1987-93). Despite educational, social and employment legislation aimed at ensuring great integration into the community, qualitative and quantitative analyses of 'quality of life' outcomes in this group produced a disappointing picture of a narrow range of leisure opportunities, negligible placement in employment, and continuing dependency on parental caregivers in adulthood. Two case studies illustrate how, in the absence of any improvement in opportunities for real integration into the community and in provision of resources to support meeting the special needs of those with learning difficulties, a marginalized group may be being created.*

**Tisdall, E. K. M. (1994). Why not consider citizenship?: A critique of post-school transitional models for young disabled people. Disability & Society, 9(1), 3-17.**

*The transition from school to 'adulthood,' for young disabled people, is generally considered difficult by the relevant literature and service providers in the field. The present transitional models, however, both lack a consensus on the criteria for a 'successful' transition and fail to incorporate the young people into the debate. The young people can be treated with little respect and given little control in transitional decisions, particularly as three negative statuses are typically attributed to them when they face transitional services: of being crisis-ridden adolescents, of being needy clients, and of being marginalized members of society. Instead, a transitional model based on citizenship is advocated, which would include re-locating the debate over 'successful' transition criteria with disabled people, altering the present 'transitional service' systems to revolve around the young people, and greater connections between disability advocacy organizations and young disabled people.*



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